

“How Many of These Surgeries Have You Done?”

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Bioethics, Public Health, and the Social Sciences for the Medical Professions

An Integrated, Case-Based
Approach

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Learning Objectives

1. Describe the ethical and legal models of informed consent and begin to apply these models at the bedside.
2. Analyze the nature and extent of the duty to obtain informed consent.
3. Begin to appreciate the complex relationship between ethics, law, and medicine.
4. Begin to demonstrate the ability to take the perspective of the patient or family in the healthcare practitioner-patient-family interaction.

Case Background

You are a first-year surgical resident. You have been instructed by the attending surgeon to get consent today from a patient who was admitted overnight. The patient, Patrice West, is a 73-year-old woman who was admitted after an abdominal aortic aneurysm (AAA) was identified. She is currently stable but urgently requires a procedure to repair the AAA. You have never seen an AAA repair; however, you think you understand enough of the technique to give Ms. West a simple explanation. You feel energized to be able to assist in a surgery that is new to you.

3.1 Background Questions

1. What types of information are physicians and other healthcare practitioners legally required to tell patients in the informed consent process? Find a court case from the last 20 years that addresses informed consent in your state. What was the decision in that case? What is the standard of disclosure applied in the case?
2. Are physicians legally required to provide information about their professional experience; for example, how many times the surgeon has done the recommended procedure? Are they legally required to disclose HIV (human immunodeficiency virus) status, history of drug or alcohol abuse, disability, financial conflicts of interest, or other personal characteristics?
3. Under the Affordable Care Act, the Centers for Medicaid and Medicare Services

developed the "Physician Compare" Website. What was its intent? Quality measures were included in the available data. What are the limitations of these data? Can you find information about local surgeons on this site?

4. What is the definition of a surgical complication? Identify the known rates of complications for an abdominal aortic aneurysm (AAA) repair.
5. What is the ethical model of informed consent? How much is it reasonable to expect patients to understand? What is health literacy?
6. How does the cultural background of the patient affect the informed consent process? Identify two examples. Drawing from these two examples, how should the informed consent process be modified to accommodate patients cultural backgrounds?
7. What are the four recognized exceptions to informed consent, that is, situations in which informed consent is not required? Describe each of these exceptions.

3.2 Additional Case Information and Questions for Discussion

When you enter Ms. West's room, her mother, her brother, and three adult children are all crowded into the hospital room. You hand Ms. West the standard procedural consent form for an open abdominal surgery and start the conversation. Before you can say much, Ms. West's family starts to interrupt with questions. Her daughter wants to know how many of these procedures your attending surgeon has performed. Her brother wants to know whether you will be in the operating room (OR) and if so, what your role will be. Her older son says while in the waiting room, he did an Internet search of AAA repairs and wants to know why an endoscopic repair is not being recommended. Her younger son asks simply, "Could my mom die?"

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1. How would you approach this situation? What would you say or do first in response to the family's questions?
2. Should you have told the attending surgeon that you had never seen the procedure performed and therefore should not be the person to obtain consent?
- (a) Self-reflection: What do you think you would do in real life? Do you think you would speak up?

Contemplating the family's first question, you are unsure how many similar procedures the surgeon has performed before, but you know that she completed fellowship training only 6 months prior.

3. Does this change your view about obtaining informed consent?
4. Do surgeons, or healthcare practitioners in general, have a duty to inform patients of their prior experience performing the procedure?
- (a) Do you think that reasonable patients would want to know how often their surgeon has done the recommended procedure?
- (b) Should patients always choose the most experienced provider? Why or why not?
- (c) You were asked a direct question about surgical experience. What would you say?
- (d) What are the ethical and legal consequences of lying?
5. How would medical education be affected if patients refused to see healthcare practitioners in training and junior healthcare practitioners because they lack experience?
6. How should you respond to the question, "Could my mom die?"

Public reporting of quality measures in patient outcomes has become more common. As an example, since 1994, the New York State Department of Health has collected and made available patient

mortality data for interventional cardiologists [1]. Some health systems have chosen to generate public "report cards" for their organizations.

7. Do you think that there is a duty to share surgeon-specific morbidity and mortality rates for procedures, allowing patients to compare surgeons?
- (a) If so, to whom would you compare?
8. Patients may want to know other "personal characteristics" such as drug or alcohol abuse, physical or mental impairment, or HIV status. Is there an affirmative duty to share this information in the informed consent process?
- (a) If the patient asks, are you obligated to provide an honest answer?
- (b) Creative Problem-Solving: Are there better alternatives that balance patient welfare and healthcare practitioner privacy?
9. Self-reflection: Of the above (provider experience, provider or institutional outcomes for a procedure, provider personal characteristics), what, if anything, would you want to know, for yourself or your family member?
- (a) Does it, or should it, matter if some personal characteristics (e.g., a prior history of alcohol abuse or HIV status) might trigger patients' biases, rather than lead to more informed decisions that produce better outcomes?
10. If your answers to any of the above questions were affirmative, do you think the law should be changed to reflect this?

About 3 months earlier, your co-resident admitted a patient with the same condition as Ms. West. You were not involved with that patient's care but you heard the story from your co-resident. You heard that the patient's daughter was a prominent physician in New York City and that the patient was privately transferred to a larger hospital to consult with a nationally known vascular surgeon. You do not know very much about Ms. West's family—just that she has Medicaid, not private insurance.

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11. Is there an obligation to transfer Ms. West to a better-equipped hospital with a more experienced surgical staff?
- (a) Should a decision to discuss transfer take into account whether the family has the resources and ability to travel to a more distant center to see a specialist?
- Is it important that Ms. West has Medicaid, rather than private insurance?

As you attempt to tactfully navigate the family's questions, Ms. West's mother looks increasingly distressed. She finally says that she is 94 years old and "in her day" it was not uncommon for residents to be allowed to operate unsupervised on poor black patients like her family.

12. How should you respond?
13. What can you, as a healthcare provider, do to address medical mistrust?

Residents are much more closely supervised now and institutionally sanctioned discrimination no longer openly occurs. However, many residents still seek out academic programs and teaching hospitals in underserved communities because they feel they are allowed to "do more" than in private hospitals serving more affluent and educated populations.

14. Is this a just system? Why or why not?
15. Self-reflection: If you were having surgery, would you allow a resident to assist? What if the patient was your parent? Your child?

3.3 Answers to Background Questions

1. What types of information are physicians and other healthcare practitioners legally required to tell patients in the informed consent process? Find a court case from the last 20 years that addresses informed consent in your state. What was the decision in that case? What is the standard of disclosure applied in the case?

The doctrine of informed consent can be understood as the union of two concepts: (1) disclosure of information so the patient possesses relevant facts and (2) obtaining the patient's voluntary authorization to proceed with diagnosis or treatment—in other words the patient's consent. This question concerns the physician's or other healthcare practitioner's fundamental duty to disclose information to patients. Additional features of informed consent are addressed in question 2.

It is well-established in law and ethics that in the physician-patient relationship, the physician must make certain "core" disclosures to patients as part of the process of enabling patients to make informed decisions to consent to or refuse treatment. Physicians must provide patients with relevant information about (1) the nature of their medical condition, including diagnosis and prognosis; (2) the risks, benefits, and burdens of the recommended treatment or procedure; and (3) the risks, benefits, and burdens of reasonable alternatives, including the option of no treatment. In turn, informed decision-making means that patients understand and reason about this information in order to reach a decision to consent to (to authorize) or refuse the treatment or intervention. Further, reasoning to a decision requires that the patient have a set of values that shape their goals for treatment. Disclosure is an affirmative duty that recognizes the knowledge and power divide between physician and patient. It would run counter to patient autonomy and well-being to expect patients to present their physicians with a long list of questions or to limit information sharing to the physician's responses only to specific patient queries [2].

The information to be disclosed is what is reasonable and relevant under the circumstances. Generally, physicians are not required to disclose very remote risks that are highly unlikely to occur. However, the law in some states does require telling patients about very serious risks of death or severe disability.

even if these risks are highly unlikely. The parameters of what is reasonable and relevant mean that it is not necessary to develop and present to patients a laundry list of all conceivable risks, though some surgical consent forms give that appearance.

The phrase "standard of disclosure" refers to the nature and scope of information physicians must by law tell their patients. Most of informed consent law initially emerged from case law. In these cases patients suffered a bad outcome from a treatment or procedure and, looking back, claimed that their injury resulted from an undisclosed risk of the procedure, and further that had they been informed of the risk they would have chosen a different approach to treatment or refused the procedure and treatment altogether. In order to determine whether the physician had a duty to disclose the risk information in question, courts had to decide on a standard of disclosure that defines the scope of the duty. Two legal standards have emerged nationally. The first and older standard is the professional, physician-oriented standard that requires physicians to disclose information that is reasonable and customary for physicians in the same or similar circumstances (e.g., the same specialty, same type of patient) to tell patients. The more recent standard is the objective reasonable patient-oriented standard that requires physicians to disclose information that a reasonable patient would want to know under the circumstances (e.g., the same or similar medical condition and treatment options). As one can imagine, in a contested case, the professional standard tends to favor physicians, as it would be other physician-experts who are called upon to attest what is customary and standard practice. By contrast, the reasonable patient-oriented standard is more favorable toward patients, as it would be lay people imagining themselves in the patient's place who are called upon to attest or determine (perhaps as members of the jury) what a reasonable patient would want to know under the

circumstances. At present, states across the country are evenly divided: about half of states follow the professional standard, and about half of states follow the reasonable patient standard [3]. However, in practice physicians more often adopt the reasonable patient standard of disclosure because it is more closely aligned with the ethical model of informed consent, discussed below.

- 2. **Are physicians and other healthcare practitioners legally required to provide information about their professional experience; for example, how many times the surgeon has done the recommended procedure? Are they legally required to disclose HIV (human immunodeficiency virus) status, history of drug or alcohol abuse, disability, financial conflicts of interest, or other personal characteristics?**

The law of battery holds that any unauthorized touching of the body is an offense and a violation of law. In health care this means that laying hands on the patient to do a physical exam or providing a treatment intervention without consent is a violation of the patient's rights of consent and refusal and a battery. The common practice to obtain written consent to surgery on the surgical consent form developed in large measure to protect surgeons from claims of battery. The typical consent form names the surgeon selected by the patient. But whether and how to ensure that this is an informed choice has received scant attention.

While there is a strong autonomy-based argument that the typical patient should be told about surgical experience, the question here is whether the law of informed consent includes (or should include) an affirmative duty to tell patients about surgical experience.

Overall, a small number of courts support the principle that informed consent should include disclosure of surgical experience. These same cases offer some support for a legal duty to disclose surgical outcomes and to refer patients elsewhere if another hospital is

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significantly better equipped for this type of surgery. The leading case is *Johnson v. Kokemoor* (discussed in the box at the end of this chapter). However, more often courts have confined informed consent to disclosure of clinical information; in other words, they have maintained the traditional parameters of informed consent described above. Another lesson from this body of cases is that if the patient asks about experience or batting average, there is a duty to answer truthfully [4].

There are other "personal characteristics" that patients may want to know about, such as the surgeon's HIV status, history of alcohol or drug use, disability that impairs surgical performance (consider the neurosurgeon with even a slight loss of fine motor skills), or financial conflicts of interest (is the physician being paid to prescribe this company's drug or use its medical device?) Each of these conditions (and there may be others) poses a potential risk to patients. As with surgical experience, from the standpoint of respect for patient autonomy, there is a strong argument that patients should be told about these risks and be given the opportunity to consider them in their choice of surgeon. However, there is no ethical or legal consensus regarding these questions. Only a handful of cases have presented this view in court.

In one case early in the HIV epidemic, the court ruled that a surgeon had an obligation to inform his patients that he had AIDS (acquired immunodeficiency syndrome) [5]. Around the same time, the U.S. Centers for Disease Control and Prevention (CDC) mandated universal precautions in the care of patients to prevent transmission of HIV and issued widely adopted policies further designed to protect both patients and healthcare providers. Current CDC guidelines call on hospitals to implement infection-control programs and to establish expert review panels to evaluate whether an HIV-positive physician should be permitted to perform exposure-prone procedures. The guidelines state that "HCWs [health care workers] who are infected with HIV

or HBV [hepatitis B virus] (and are HBsAg positive) should not perform exposure-prone procedures unless they have sought counsel from an expert review panel and been advised under what circumstances, if any, they may continue to perform these procedures. Such circumstances would include notifying prospective patients of the HCW's seropositivity before they undergo exposure-prone invasive procedures" [6].

Courts generally do not require physicians to tell patients about drug or alcohol abuse, unless it is a current problem that increases the risks of physician impairment and incompetence [7]. Some law supports the view that potential financial conflicts of interest must be shared with patients, in both the clinical and research context [8]. Overall though, the law has maintained its traditional focus on disclosure of medical information and has not done much to expand informed consent to impose an affirmative duty to tell patients about so-called personal characteristics of the physician.

3. Under the Affordable Care Act, the Centers for Medicaid and Medicare Services (CMS) developed the "Physician Compare" Website. What was its intent? Quality measures were included in the available data. What are the limitations of these data? Can you find information about local surgeons on this site? The Affordable Care Act included a requirement for CMS to create and make accessible the "Physician Compare" database. The intent of the database is "to help consumers make informed decisions about their health care and to create clear incentives for physicians to perform well." The "Physician Compare" Website has general information about physicians who participate in Medicare including their clinical training, specialties, board certification, and practice information (e.g., site information). In addition, the Website includes information about quality measures and participation in certain programs such as "Maintenance of Certification Program" [9].

More than 50 quality measures are available for both group practices and for individuals. Examples of quality measures available for both group practices and individual clinicians include rate of Influenza vaccination, rate of giving statins to patients at risk for heart disease, and assessment of spirometry evaluations in patients with chronic obstructive pulmonary disease.

The data for the quality measures were obtained through multiple sources including but not limited to claims data and data from required registries. The limitations on the data include that they represent Medicare patients only; that claims data represent claims rather than actual delivery of care and that there is necessarily a significant delay in reporting of those data; and that some of the performance data are self-reported [10].

4. **What is the definition of a surgical complication? Identify the known rates of complications for an AAA repair.**
The key elements to consider for a complication of a surgical or medical procedure include (1) that there was an unexpected outcome that impacted the patient and (2) this outcome was the result of the procedure being done. Dindo and his colleagues defined complications "as any deviation from the normal postoperative course. This definition also takes into account asymptomatic complications such as arrhythmia and atelectasis. A sequela is an 'after-effect' of surgery that is inherent to the procedure (e.g., inability to walk after an amputation of the leg)" [11].

If surgery is indicated for a person with an infrarenal abdominal aortic aneurysm, there are two main surgical approaches: an open repair through a large abdominal incision and an endovascular repair typically through a femoral catheter. The latter is considered a less risky procedure for patients who qualify. Both procedures can have complications associated with bleeding, wound or graft infections, kidney damage, blood clots with potential loss of blood flow to the

legs, and spinal cord injuries. Other complications associated with open repairs include cardiac complications (heart attacks and arrhythmias), bowel injury, and pulmonary complications. Other complications associated with endovascular repair include blood vessel damage or damage to other organs as a result of the catheter and endoleaks (ongoing leaking out of the graft) [12, 13].

The distinctions and relationships between complications, medical errors, and negligence are explored in ► Chapter 17.

5. **What is the ethical model of informed consent? How much is it reasonable to expect patients to understand? What is health literacy?**

The ethical model of informed consent is grounded in the physician's duty to promote patient autonomy in the physician-patient interaction. Respect for patient autonomy also promotes patient well-being, as it fosters healthcare decisions based on the patient's own values and personal goals. Further, respect for patients fosters trust; this in turn encourages patients to be forthcoming in describing their health concerns and goals for care and treatment. The ethical model emphasizes that the physician's role is not merely to provide information, but also to facilitate and assist the patient to understand the nature of their medical condition and the risks, benefits, and burdens of treatment alternatives, in order to make voluntary autonomous informed decisions. The requirement of voluntariness recognizes that patients do not make their own decisions if they are coerced or unduly manipulated by others (perhaps a controlling family member). Most patients act voluntarily, but they cannot exercise their autonomy if they do not understand essential information about their medical condition and diagnostic or treatment options. A rigorous commitment to respect for patient autonomy means engaging the patient to take a thorough history and recognizing and responding to the patient's personal, subjective concerns, and

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informational needs. Another element of the ethical model of informed consent is the call to explain things in language the patient can understand. The ethical model emphasizes the quality of consent through the promotion of patient autonomy in the physician-patient interaction [14]. By contrast, the rationale for the legal model also rests on respect for autonomy, voluntary choice, and self-determination, but its near-exclusive focus on information disclosure does little to promote the quality of the consent process.

The gap between the theory and practice of informed consent has been much discussed [15]. Concerns about the quality of the consent process often focus on how much patients should understand to make informed decisions. Patients should have at least adequate understanding for the decision to be made and should know that they have the right to consent to or refuse the physician's recommendation. But there is no minimum standard of comprehension that is widely accepted. To expect full understanding, akin to that of the physician, would be too demanding and would mean that few patients would be able to make truly informed decisions. Faden and Beauchamp, leading experts on informed consent, propose a benchmark of "substantial understanding," meaning that patients' understanding of the relevant information and of their rights is substantially accurate [14]. But this threshold and expectation may be too high, as patients often do not have a highly accurate and thorough understanding (let alone a full understanding), especially when the relevant clinical information is complex.

Whether patients possess sufficient health literacy to give meaningful informed consent is a complex matter. The 2004 report on health literacy from the Institute of Medicine found that "[n]early half of all American adults—90 million people—have difficulty understanding and acting upon health information" [16]. Health literacy can be described as the extent to which patients can access,

process, and reason about health information. Health literacy compasses a range of skills and abilities: reading, writing, communication, and comprehension of medical information and of numbers and statistics (numeracy). Facility with computers and other computer devices is an increasingly important element of literacy. Limited health literacy has been found to be more common in the African American and Hispanic populations and among the elderly. It has also been associated with decreased attention to preventive care, lower immunization rates, and higher rates of non-compliance such as taking medications as prescribed [17].

There is a growing number of proposed tools and approaches intended to improve patient understanding and the informed consent process [18]. Consent forms and patient education materials have been revised, produced, and evaluated at a more appropriate reading level for the average patient (the eighth grade level is an accepted target). One oft-used measure of understanding and literacy is the patient's ability to teach back (repeat back) what has just been discussed with the physician [19]. What is reasonable to expect of patients will vary with the nature and complexity of the patient's condition and treatment options, and the physician will need to assess in each case whether the patient has sufficient understanding to make an informed decision. Here again, good communication will reveal clues as to the patient's level of health literacy. Another factor that plays an important role for many patients with respect to health literacy and informed consent is the patient's cultural background.

6. How does the cultural background of the patient affect the informed consent process? Identify two examples. Drawing from these two examples, how should the informed consent process be modified to accommodate patients' cultural backgrounds? Broadly defined, "[c]ulture refers to integrated patterns of human behavior that include the language, thoughts, actions,

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customs, beliefs, and institutions of racial, ethnic, social or religious groups" [20]. Cultural differences have been shown to be related to racial and ethnic disparities in health and health outcomes [21]. Here we briefly mention three common sorts of issues that can arise in the informed consent process when the patient (or the patient's family) is of a significantly different culture from the physician's.

First, and directly related to health literacy, when the patient is not fluent in the English language, use of a translator may be warranted. Patients have a legal right to a translator, and hospitals are required to make translator services available. Use of family members as translators is generally discouraged, as there is potential for families to share information in accordance with their own views of their loved one's best interests. As with health literacy in general, physicians should strive to avoid medical jargon. In some cases use of translated written materials may be an effective tool.

Second, some cultures place less importance on patient autonomy. For some patients it is family members who are the primary decision-makers, and this may extend to insistence that a grave prognosis not be shared with the patient [22]. In Amish culture, where some aspects of Western medicine are not accepted, it is men and elders of the community who are typically recognized as deciders. In some cases, decision-making may not be fully patient-centered, as community values and resources can play a significant role where the costs of care are very high.

Third, patients sometimes make decisions based on their personal religious or ethnic values that seem contrary to the patient's own best interests. Perhaps the best known example is refusal of lifesaving blood transfusions by members of the Jehovah's Witness faith [23]. In end-of-life care, religious faith is the reason some patients insist that "everything be done," even when facing extremely poor quality of life. And some patients reject their physician's recommendation in favor of

culturally embedded alternative remedies, while others may harbor deep distrust of the healthcare system or broadly reject Western medicine.

Education and training in cultural awareness and humility for medical students and residents with the goal of promoting a process of culturally sensitive patient-centered informed consent has received considerable attention in recent years. Some emphasize the physician's duty to become familiar with different cultures in their patient population. Other initiatives focus on how to frame the physician-patient interaction to elicit how social, economic, religious, and cultural beliefs influence the patient's understanding of their illness, their health values, goals, and behaviors, as well as the role of family in care decisions [24]. A team approach that includes religious or community leaders, spiritual care, and social work may be considered. The healthcare practitioner should remember that patients from particular ethnic or religious groups are always individuals with their own views and interpretations of the place of culture in their health care. For example, even a self-identified devout Catholic may not adhere to all of the official tenets and teachings of the Catholic faith. This subject is also explored in ► Chapters 10 and 13.

7. **What are the four recognized exceptions to informed consent, that is, situations where informed consent is not required? Describe each of these exceptions.**

There are four generally recognized exceptions to the requirement of informed consent. They are (1) decisional incapacity, (2) waiver, (3) therapeutic privilege, and (4) emergencies [25].

- **Decisional (in)capacity:** In order to make informed decisions, patients must have the capacity to put autonomy into action. Decisional capacity means that the patient possesses the ability to understand and appreciate (1) the nature of his or her medical condition, including diagnosis and prognosis; (2) the benefits, risks, and

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burdens of the recommended treatment and reasonable alternatives, including the option of no treatment; and (3) to reach and express an informed decision. Patients are legally presumed to have decisional capacity if they are 18 years of age or older. Under law, adolescents have the right to make certain healthcare decisions, such as those concerning sexual activity and reproduction, when under the age of 18. (Decision-making in pediatrics is further discussed in ► Chapters 7, 9, and 19. Decision-making for and by adolescents is discussed in ► Chapters 5, 10, and 21).

Decisional incapacity is the most important and most frequently encountered exception to the rule that informed consent or refusal must come from the patient herself. When the patient appears to lack capacity, it is the responsibility of the attending physician, both ethically and legally, to undertake a closer examination to assess capacity. If the patient is deemed to lack capacity, the locus of decisional authority shifts away from the patient to an appropriate surrogate decision-maker, such as a healthcare proxy, spouse, or adult child. Often, the attending physician will request a consultation from a psychiatrist to further evaluate the patient's capacity ("call psych"), but in most cases it is up to the attending physician to make the final determination of capacity. Sometimes the law requires consultation with psychiatry or an appropriately trained professional if the patient suffers from intellectual disability or has a history of developmental disability.

Several important points about capacity should be kept in mind. Capacity is decision-specific; it is about the patient's abilities to make a particular decision and may vary depending on the nature and complexity of the decision. A patient may

have capacity to make one decision (e.g., "my son should make decisions for me if I become unable to do so") but not other more complex decisions (e.g., "should I have surgery to repair my aneurysm?"). Capacity is about the patient's ability to make decisions at a particular time. Some patients have fluctuating capacity; they are unable to make a treatment decision today, but tomorrow when antibiotics have taken effect or pain medications have been reduced, decisional capacity may be restored. Respect for patient autonomy includes treating cognitive impairment to enhance opportunities to make informed decisions. Lastly, it is often said that capacity is not a status-based judgment. Patients are not to be deemed to lack capacity simply because they are depressed, disabled, elderly, or have an intellectual disability. Rather, these conditions should be taken as indications that call for a closer look at the patient's capacity.

Physicians tend to accept that patients have capacity and are making informed decisions when they agree with the recommended course of treatment and are more inclined to question capacity when patients disagree. Physicians may believe that the patient who refuses the recommended treatment is choosing contrary to their own best interests and sometimes deem the patient to lack capacity for this reason. However, patients do not lack capacity simply because they disagree with the physician's recommendation. This may be an indication that capacity should be carefully assessed, but respect for autonomy means that patients have the right to make the "wrong" decision, based on their own values and goals.

Finally, capacity should be distinguished from the legal term "competence," though they are often used interchangeably. When courts

determine that a person is incompetent, this typically means the person is unable to manage their affairs and to make a range of types of decisions for himself, and someone else needs to be appointed to act on the person's behalf. By contrast, physicians make determinations about patient capacity every day without any involvement of the court system [26].

— **Waiver:** Suppose the patient says, "Wait, wait, don't tell me, Doctor. Tell me what to do, I trust you." Perhaps, the patient frames it as, "Doctor, what would you do? That's good enough for me." Does the physician still have a duty to provide all relevant information, or has this been waived by the patient? Can the physician proceed to obtain the patient's signature on the consent form or otherwise document consent in the progress notes? Taking respect for patient autonomy and the right to decide seriously means the physician should continue to engage the patient in a dialogue that presents relevant information and clarifies the risks, benefits, and burdens of the recommended intervention. At the same time, to honor the patient's waiver is also to respect an autonomous choice not to know.

Reliance on the patient's waiver of information is disfavored in both law and ethics. However, there may be rare cases where accepting a waiver of information is appropriate. To rely on a waiver, patients must voluntarily and intentionally give up the right to more information, knowing that they are entitled to receive the information and that the decision to accept or refuse treatment belongs to them and not to the physician. It must be a knowing waiver. Thus, persistent refusal of information by itself does not constitute waiver. Nor is the patient who simply avoids the conversation waiving the right to know. This is not to say that physicians have an affirmative duty to recite these rights for the patient, but

rather when the patient indicates a desire not to know, then it should be a prompt to establish that the patient knows their rights of informed consent. One approach would be to refer to and discuss the patients' bill of rights that is typically included in patient intake materials and posted in the halls of hospitals. To go one step further, to rely on a waiver physicians should offer accurate information (not downplay the risks) and assess whether the patient is refusing specific facts, such as prognosis, the nature of the procedure, the risks and likelihood of a good or bad outcome, or the side effects. The informed consent conversation including the patient's waiver and the signing of any consent forms should be clearly documented in the patient's record.

Other important questions about waiver may arise when patients choose to look to family members to make treatment decisions for them ("Doc, ask my daughter"). In some cultures it is common for families, not patients, to be the deciders. Families are trusted to decide in the patient's best interests and in accordance with the patient's wishes. Sometimes patients want to know but not decide; other times they may direct that family be informed and also give consent [27]. When the patient is from a different ethnic or cultural background that values family authority over patient autonomy, the physician should clearly establish this preference before looking to family for consent. Often it will be ethically appropriate to respect patient and family cultural norms and accept this choice as a form of waiver. However, in some cases, such as where the family is making a decision contrary to the patient's wishes or their best interests, the physician must act as a patient advocate and explore more rigorously the family dynamics and the basis for the family's treatment decisions.

3. **Therapeutic Privilege:** If healthcare practitioners feel that sharing information about diagnosis or prognosis will be too upsetting to the patient, they may consider not disclosing the seriousness of the patient's condition or the risks of surgery in order to avoid doing more harm than good. A variation of this concern might be understating the severity of the risks of treatment. The concept that arguably supports this approach is therapeutic privilege, the idea that healthcare practitioners have the privilege to not disclose certain information if, in their judgment, doing so would be harmful to the patient or that disclosure would not be in the patient's best interests. Therapeutic privilege held important currency in the past; however, today the doctrine is disfavored in both ethics and law. Withholding important information would be a violation of patient autonomy and undermines the right of informed consent. Further, respect for autonomy also means giving patients the opportunity to judge for themselves whether some information would be too upsetting. There is additional concern that recognition of therapeutic privilege would too often become an excuse to avoid difficult or time-consuming interactions with patients. Nor should the privilege be invoked paternalistically because the patient disagrees with the physician's recommendation, but might be persuaded to agree based on incomplete information. Note that the doctrine of therapeutic privilege would give the physician permission to limit disclosure by withholding certain information. By contrast, under the waiver exception, information is offered and the patient chooses not to know more.

Sometimes the issue of therapeutic privilege arises from the family's request that certain information be withheld from the patient ("Don't tell dad he has a terminal illness, he'll be devastated."). As noted in the

discussion of waiver, the request may sometimes be grounded in the family's ethnic or cultural norms that family decision-making takes priority over the personal autonomy of the patient. In some Asian cultures, bad news is withheld from loved ones to preserve the benefits of hope and hopefulness. In such instances the physician must balance respect for patient autonomy with both patient welfare and appropriate respect for the family who know the patient best. Putting aside the family's concerns in favor of patient autonomy can be a difficult and sensitive choice, especially where the patient is likely to lose decisional capacity with progression of their disease and family will soon assume responsibility for making treatment decisions. Still, the general rule is that patients should be told and the right to informed consent should be honored. One approach here would be to ask the patient if they want to know everything. If not, perhaps they will defer to family. The question of waiver, rather than therapeutic privilege, would then become the better way to understand the consent process. In rare cases a grave prognosis may truly be so traumatic as to impair the patient's capacity to make treatment decisions or may put the patient at imminent risk, for example, the patient who has manifested suicidal behavior related to their medical condition. But invocation of therapeutic privilege to withhold information should be narrowly and strictly construed.

4. **Emergency treatment:** In both ethics and law, the emergency treatment exception to informed consent is well-established. When patients suffer a sudden, serious injury or event and are in imminent need of medical attention, preventing death or serious harm takes precedence over obtaining informed consent, or even uninformed consent, from the patient. This principle also rests on the practical reality that often there

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is no time to engage the patient in conversation; treatment must begin right away. A further rationale for the emergency exception rests on the idea that consent is implied by the circumstances, meaning that we have made a societal judgment that under the circumstances emergency medical technicians, emergency physicians, and other personnel have permission to treat without stopping to seek consent from the patient.

This is not to say, however, that all "emergencies" are the same. Many ambulatory visits to the emergency room are for nonurgent conditions, for example, a broken arm or a laceration in need of stitching. In these instances there is typically time and opportunity to explain the nature of the medical condition and the recommended treatment and to obtain informed consent. Under these and other circumstances where the patient appears capable of giving informed consent, emergency physicians should be especially attentive to the patient's decisional capacity. Compared to other specialties, emergency physicians tend to see a higher proportion of patients whose mental state may be compromised by drugs, alcohol, pain, or anxiety. Also important, patients' interactions with emergency physicians are typically first-time encounters between strangers, with no prior relationship characteristic of primary care practice or patients with chronic illness. Hence, the emergency physician often must rely solely on the patient's understanding and his or her expressions of values and goals in the immediate time-limited circumstances [28].

Before you can say much, Ms. West's family starts to interrupt with questions. Her daughter wants to know how many of these procedures your attending surgeon has performed. Her brother wants to know whether you will be in the operating room (OR) and if so, what your role will be. Her older son says while in the waiting room, he did an Internet search of AAA repairs and wants to know why an endoscopic repair is not being recommended. Her younger son asks simply, "Could my mom die?"

1. How would you approach this situation? What would you say or do first in response to the family's questions?

Box 3.1 Teaching Tip

Encourage learners to think about what they would want to be told if they, or a loved one, were undergoing surgery. Ask them to consider all aspects of informed consent and whether they think a first-year surgical resident is able to address every aspect.

The resident in this situation should take a step back and consider several things. Has she clearly introduced herself and explained her role? Has she asked each family member to introduce himself or herself? Has she given Ms. West the opportunity to speak with her privately or with only one or two family members present? Though the resident may feel less pressure one-on-one, this is ultimately the patient's choice, and the resident should not insist that anyone leave. Furthermore, it is generally recommended that patients have at least one person present to help them take notes and remember all aspects of the discussion. Does everyone—including the resident—have a place to sit comfortably during the discussion? Once these steps have been taken, then she can proceed.

There is no single "right" way to start. One good approach would be to reassure Ms. West's children that the resident will answer all their questions, or find and return with answers to any she cannot answer immediately, including the last question (about whether the patient might die), but that the resident wants to start by asking Ms. West what she already knows about her condition and the procedure.

3.4 Responses to Discussion Questions

When you enter Ms. West's room, her mother, her brother, and three adult children are all crowded into the hospital room. You hand Ms. West the standard procedural consent form for an open abdominal surgery and start the conversation.

Starting with this question will allow the resident to (1) avoid repeating information that Ms. West already understands; (2) correct misconceptions upfront, before they can persist; and (3) appreciate something of Ms. West's educational background.

When the resident finally begins to explain the procedure, she should use lay language that is easy to understand

and pause frequently to make space for questions [29]. She should also allow time for "teaching back," asking Ms. West to explain in her own words what she has just been told. She needs to be able to explain the risks and benefits of the proposed surgical intervention, *as well as* any alternatives and the risks and benefits of such alternatives.

Box 3.2 Personal Perspective

In the essay "Treating Patients as Partners, by Way of Informed Consent," the surgeon Pauline Chen describes an encounter in which she fails to do this [29]. She writes:

"Have you ever had a paracentesis?" I asked, pulling out a consent form for Pete to sign.

"No," he answered between short labored breaths. "Does it hurt?"

I tried to reassure him by explaining how I would numb him first. But as I began describing the anesthetic, the bee sting prick

of the needle and the pressured sensation of medication infiltrating the flesh, I felt myself slipping into a familiar spiel, the same one I had delivered to all the other patients with intractable ascites. I pointed to the quadrant on his belly where I would work, estimated the amount of fluid I would pull out, and then reeled off the standard catalog of complications for this procedure.

Pete looked away from me and stared at the consent form. Yet even as I watched his brows

knit together, his eyes widen then wince, I kept on talking. I had gone into my informed consent mode—a tsunami of assorted descriptions and facts delivered within a few minutes. If Pete had wanted me to pause and linger over something, I never knew. He couldn't get a word in edgewise.

"So," I finally asked him at the end of my monologue, "do you have any questions?" Even as that sentence came out of my mouth, I knew what his answer would likely be.

2. **Should you have told the attending surgeon that you had not seen the procedure performed previously and therefore should not obtain consent?**

Yes. Never having witnessed such a surgical procedure necessarily limits the resident's ability to fully engage the patient and her family, as the resident is likely to be unable to adequately respond to certain questions that the family may have during the consent process such as, "What have your experiences been with this procedure?" If the resident is not prepared to engage in the informed consent interaction with the patient and family, then he cannot do so ethically. The first obligation is to the patient: to her role and authority in the decision-making process and to promoting her well-being and best interests. Residents may feel embarrassed to tell attending physicians that they lack the necessary knowledge and experience to obtain consent, but this obstacle must be overcome.

- (a) **Self-reflection: What do you think you would do in real life? Do you think you would speak up?**

Box 3.3 Teaching Tip

"Speaking up" is explored in-depth in ► Chapter 20

Contemplating the family's first question, you are unsure how many similar procedures the surgeon has performed before, but you know that she completed fellowship training only 6 months prior.

3. **Does this change your view about obtaining informed consent?**
This indicates that the resident has some more information to share with the patient and her family. The resident can tell them about the attending physician's training and may be able to make some inferences about the surgeon's experience with particular procedures. It does not answer the specific question of how often the surgeon has performed this procedure. Providing this information opens

up the possibility that the patient and her family may be happy that they have a younger, more recently trained surgeon, who is likely familiar with the most current surgical techniques. It also opens the resident up to more questions about the attending surgeon's experience, given that she has only recently completed fellowship training. While the resident should be prepared to answer these types of questions, she still needs to do more research before the family's question can be fully answered.

4. **Do surgeons, or healthcare practitioners in general, have a duty to inform patients of their prior experience performing the procedure?**

To some extent, there are strong ethical grounds for surgeons and physicians to volunteer how often they have done the procedure, but it is more firmly established that one's knowledge and training should be explained. Indeed it is hard to imagine explaining the surgery to the patient without demonstrating one's knowledge of the procedure, and this is a natural place for the surgeon to comment on his or her training and experience with the procedure. In this case, the question has already been asked, so it is incumbent on the surgeon to give a forthright answer.

(a) **Do you think that reasonable patients would want to know how often their surgeon has done the recommended procedure?**

Increasingly, patients seek information about a surgeon's credentials or the hospital's surgical program online. There is substantial evidence that in addition, most patients would want to know how often the surgeon has performed their procedure and would take this into account in their choice of surgeon. In two studies of emergency room patients at Vanderbilt University, approximately two-thirds of patients wanted to know about the resident's experience with the procedure [30] and what the role

of medical students would be [31]. Another study of cancer patients at Johns Hopkins University found that most patients rated as "very important" knowing how many times the surgeon had done their procedure and how many years the surgeon had been in practice [32]. Other studies also reveal a strong interest in knowing whether this would be a first-time procedure for the resident [33].

Regardless of an individual healthcare provider's view of what a reasonable patient would want to know, or the legal standard of disclosure in a particular state, what matters to the patient should not be ignored. The patient's personal, and perhaps unusual or idiosyncratic, concerns can play a pivotal role in the decision to accept or refuse the recommended treatment plan. Consider, for example, the rock guitarist who is especially sensitive to even the slightest loss of dexterity following shoulder surgery or the master chef who cannot afford even the slightest loss of taste as a side effect of medication. Perhaps in this case the family knows firsthand of a surgery that went bad with an inexperienced surgeon. The physician may and should become aware of such concerns through the taking of a good social history and the process of communication and interaction with the patient.

(b) **Should patients always choose the most experienced provider? Why or why not?**

This argument has intuitive appeal. After all, who would not choose the more experienced surgeon over the first-year resident? Who would not recommend that a family member go to see the surgeon with the best track record of good outcomes for the procedure they are facing? However, the assertion that patients would routinely flock to more experienced surgeons seems

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to be based more on speculation than factual evidence. One reason is that focus on surgical experience alone oversimplifies the way in which people choose physicians. Patients typically look to primary care physicians, family, friends, or co-workers for recommendations. Some patients consider the surgeon's medical school, certification, or other professional qualifications. For some, hospital reputation is important. For others, gender and ethnicity are important considerations. Further, once relationships between patients and providers are established, trust, familiarity, and rapport may lead patients to choose to continue care, even if given the option to transfer to a more experienced provider.

Cost and location can also be major considerations. Insured patients have strong financial incentives to choose from the panel of surgeons that participate in their health plan and thus face restricted choice. Further, staying in network and the higher costs of going out of network also limit patients' choice of hospitals. In sum, many patients want to know about surgical experience, but this may be only one of a number of factors taken into account when choosing a surgeon.

Finally, experience is not the only factor in determining physician competence and driving outcomes. Some senior physicians will have little recent, direct experience performing procedures, if they have primarily supervised residents and fellows; others, particularly outside of academic institutions, may not be as up-to-date on changing practice standards. And training with new and innovative equipment and techniques, much of which occurs post-residency, can be even more uneven. Pointing to these variations in surgical practice, some argue that experience and outcome statistics

are misleading and should not be routinely shared with patients.

- (c) **You were asked a direct question about surgical experience. What would you say?**

The resident could simply say that she does not know, but a better response is to also offer to ask the attending physician to come talk to the patient personally. Alternatively, the resident could offer to find out and report back to the patient, proceed to obtain the data to the best of his ability, and be prepared to explain it. If the resident does seek out the answer, both ethically and legally, she has an obligation to tell the truth. Truth-telling is a core ethical value in medicine. There are resources available to the resident, including the library, patient educator, the Internet, and of course the attending surgeon.

- (d) **What are the ethical and legal consequences of lying?**

Lack of honesty in the physician-patient-family relationship can mean loss of trust and rapport in that relationship. In response, patients may be less forthcoming about their condition, their concerns, and goals for treatment, and the quality of care can be compromised. In some cases, when trust is broken, patients may choose to find another physician. Fraud, misrepresentation, and manipulation in the informed consent process can lead to professional disciplinary actions and even lawsuits from patients for violation of the right of informed consent or fraud.

5. **How would medical education be affected if patients refused to see healthcare practitioners in training and junior healthcare practitioners?**

Medical education, and the next generation of well-trained qualified healthcare practitioners, requires that most patients be willing to allow trainees to participate in their care. Most patients, most of the time, do allow trainees to participate and

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to learn in their care and treatment with the understanding that the trainees have adequate supervision (Supervision of trainees is discussed further in ► Chapter 20.) Most identify with the fact that to acquire the skills and abilities of any medical profession takes practice. Experience matters on the learning curve. Another perspective, perhaps implicit in patients' willingness to have residents and students involved in their care, is that doing so is part of the social contract and that the social contract entails obligations to future generations to assure that they will benefit from a high-quality healthcare system. If done appropriately and honestly, most patients will allow students and trainees to assist in their care.

Box 3.4 Teaching Tip

It may be appropriate to explore the limitations of this idea now or later in the discussion. For instance, is a physician-parent justified in refusing to allow trainees to participate in his child's surgery? Should a physician who is a patient, say in labor, decline to have trainees present for the birth? All trainees, or just those known to her or whom she might later supervise? What about a child who has been sexually abused and whose parents would like to limit the number of people examining her?

6. How should you respond to the question, “Could my mom die?”

If there is a meaningful risk the patient could die—whether in the operating room, in recovery, or after discharge (what is the expected survival post-discharge?)—then these risks need to be presented to the patient with opportunity for the patient to ask questions. The patient cannot make an informed decision to have or decline the surgery without considering this possibly significant risk. For Ms. West, who needs her AAA repaired, the risk of death is significant and must be discussed. Many states require by law that the risk of death be disclosed even if that risk is considered remote.

As with any procedure, the physician who is obtaining consent from the patient needs to tell her of the risks inherent with an AAA as well as the benefits and risks of the indicated surgical procedure. Prior risk factors pertaining to a patient's history and habits seem to dramatically affect morbidity and mortality associated with AAA repair. If surgical repair has been recommended, it is reasonable to assume that Ms. West is at risk for rupture of her AAA. Without surgical intervention, rupture of an AAA will result in death. Given the gravity of the underlying medical condition, it is imperative that the risks of the AAA repair are shared in the context of the life-threatening condition. Information about complications should be shared with the family only with Ms. West's consent.

Public reporting of quality measures in patient outcomes has become more common. As an example, since 1994, the New York State Department of Health has collected and made available patient mortality data for interventional cardiologists [1]. Some health systems have chosen to generate public “report cards” for their organizations.

7. Do you think that there is a duty to share surgeon-specific morbidity and mortality rates for procedures, allowing patients to compare surgeons?

Although some commentators have argued that surgeons should have a legal duty to share their morbidity and mortality rates, for the most part, the law imposes no such obligation. Ethically, there are several different arguments that apply here. Those in favor argue that this information is important to patients because they are not just consenting to a specific procedure, but to a specific procedure done by a specific provider, and this information is part of the risks, benefits, and consequences of the procedure. It is therefore relevant to making an informed decision. On the other hand, those against such a duty emphasize that understanding these statistics is a complex matter and may confuse more than help patients to make informed decisions.

They emphasize, for example, variables of patient mix, different patients' overall condition and comorbidities, and the quality of surgical centers. Further questions to consider are whether the resident can in fact obtain comparative statistics for other surgeons who have done this procedure and whether that information, if available, will be current and up-to-date.

(a) **If so, to whom would you compare?**

Comparison might take place between physicians within the same institution, between physicians or institutions in the same geographic area, or between physicians or institutions in the USA (or even globally). All of these groups may be of interest to some patients, but many patients may not have the time or resources to get second opinions from physicians further afield. Furthermore, they may themselves differ in clinically significant ways from the patient population in the geographic area or nationally—an important factor that can limit the usefulness of comparisons to other surgeons.

✓ 8. **Patients may want to know other "personal characteristics" such as drug or alcohol abuse, physical or mental impairment, or HIV status. Is there an affirmative duty to share this information in the informed consent process?**

The law generally does not require physicians to volunteer to tell patients about drug or alcohol abuse or disability. Rather, the traditional boundaries of informed consent have been maintained. Concerns for the privacy of physicians and the sometimes fuzzy line between one's professional and personal life also counsel against requiring disclosure. Still, there may be an obligation to do so if there is a current problem that increases the risks of physician impairment and incompetence.

(a) **If the patient asks, are you obligated to provide an honest answer?**

Some argue that, if asked, the healthcare practitioner should always

answer truthfully. After all, truth-telling is a core value in medicine. However, it is less clear that these sorts of personal characteristics represent current risks for the patient that the patient is entitled to know, particularly when compared to surgical inexperience. Questions about drugs, drinking, or disability can conflict with healthcare practitioners' interests in protecting their privacy. For these reasons, others argue that healthcare practitioners may properly decline to answer such questions or answer only when the healthcare practitioner's current condition compromises the ability to provide competent and appropriate care. It is important to note that state regulatory agencies (e.g., medical boards) have policies in place to protect patients from impaired healthcare practitioners. There is significant variation from state to state. For example, some states require that healthcare practitioners report colleagues who are suspected of performing procedures while impaired, but others only encourage such reporting. Healthcare practitioners should familiarize themselves about their state's policies.

(b) **Creative Problem-Solving: Are there better alternatives that balance patient welfare and physician privacy?**

Box 3.5 Teaching Tip

Consider asking the learner(s) who researched Background Question 4 to comment on how easy or difficult it was to find information about the procedure and about local surgeons. How feasible would finding such information be for the typical patient or family? Thinking about it from this perspective may affect the response.

✓ 9. **Self-reflection: Of the above (provider experience, provider or institutional outcomes for a procedure, provider**

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personal characteristics), what if anything would you want to know, for yourself or your family member?

- (a) How do you think the reasonable patient would answer these questions?

- ✓ 10. If your answers to any of the above questions were affirmative, should the law be changed to reflect this?

If reasonable patients would want to know, then there is a strong ethical argument for a duty to disclose and hence a strong argument for making disclosure a legal obligation. But there are also reasons not to turn disclosure into an affirmative legal obligation. A leading objection to imposing an affirmative duty to tell patients about surgical experience and outcomes ("batting average") is that patients would regularly choose more experienced surgeons or those with a stronger track record. In turn, medical education and training would suffer, the next generation of surgeons would be less qualified, and the next generation of patients would be at risk. Much the same argument has been made in even stronger terms in opposition to mandated disclosure of surgical batting averages. It is far from clear that this same argument applies to physicians impaired by personal challenges of alcohol, drugs, or disability, as these conditions apply in particular cases rather than across a wide group of surgeons in training. However, as just noted, there are other concerns about physician privacy to be considered.

About 3 months earlier, your co-resident admitted a patient with the same condition as Ms. West. You weren't involved with that patient's care but you heard the story from your co-resident. You heard that the patient's daughter was a prominent physician in New York City and that the patient was privately transferred to a larger hospital to consult with a nationally known vascular surgeon. You don't know very much about Ms. West's family—just that she has Medicaid, not private insurance.

- ✓ 11. Is there an obligation to transfer Ms. West to a better-equipped hospital with a more experienced surgical staff?

As long as the center meets the standard of care, there is no duty to refer elsewhere. Certainly, if a patient wants a second opinion, physicians have a duty to allow the patient adequate time and even to assist in finding a consulting surgeon, as long as the risks and benefits of delaying care are understood. For example, will delaying surgery for a second opinion increase the patient's risk of a bad outcome?

If the level of experience, skills or equipment, or track record of successful outcomes is substandard, the facility should not offer that surgery. There should be outcomes data, and accreditation standards that are met, to ensure the hospital is safe and the procedures are of high quality and successful.

- (a) Should a decision to discuss transfer take into account whether the family has the resources and ability to travel to a more distant center to see a specialist? Is it important that Ms. West has Medicaid, rather than private insurance?

If the hospital meets the criteria established above, there is no obligation to have the discussion. If, however, a transfer is either medically indicated or requested by the patient, the patient's insurance status should not influence the decision to have the discussion. In the former situation, the transfer should be a covered service (e.g., if the rationale is transfer to a higher level of care); in the latter situation, if the transfer is not eligible for coverage, the patient would have to be able and willing to cover the costs personally. That is not for the physician to decide without the patient's input. The physician may not have full information regarding the family's values, beliefs, interests, and resources until all options have been explained.

Patients are entitled to decide for themselves about the burdens they

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are willing to assume to pursue care elsewhere, including the personal, social, and financial burdens. The patient's social situation, including financial resources and family circumstances, certainly matters. They should be considered but only to the extent that such considerations help patients to access the best available care and achieve desired health outcomes. Circumstances should not be "considered" in order to withhold options.

As you attempt to tactfully navigate the family's questions, Ms. West's mother looks increasingly distressed. She finally says that she is 94 years old and "in her day" it was not uncommon for residents to be allowed to operate unsupervised on poor black patients like her family.

✓ 12. **How should you respond?**

The resident should explore Ms. West's mother's fears and the implied message that the family does not trust the care she is receiving and feels she is being treated differently. It would be beneficial to address this with the attending physician, preferably before giving the impression that they are being disrespected by not having the attending surgeon perform the informed consent. Currently, all procedures performed in the OR or with significant risk must have an attending present, as per the American College of Surgeons (ACS) Statement on Principles [34].

The primary attending surgeon is personally responsible for the patient's welfare throughout the operation. In general, the patient's primary attending surgeon should be in the operating suite or should be immediately available for the entire surgical procedure. There are instances consistent with good patient care that are valid exceptions. However, when the primary attending surgeon is not present or immediately available, another attending surgeon should be assigned to be "immediately available."

✓ 13. **What can you, as a healthcare provider, do to address medical mistrust?**

Providers should be professional, honest, and trustworthy and should treat every patient as if the patient is one of their own family members. They also must be willing to speak up if they see ethical problems or lapses in standard of care, even as medical students.

Residents are much more closely supervised now and institutionally sanctioned discrimination no longer openly occurs. However, many residents still seek out academic programs and teaching hospitals in underserved communities because they feel they are allowed to "do more" than in private hospitals serving more affluent and educated populations.

✓ 14. **Is this a just system? Why or why not?**

Many believe this is not a just system because it disproportionately burdens disadvantaged patients. While many patients may in fact benefit from a student's or resident's interest in their care, patients may experience longer visits (particularly if they have to see a student, then a resident, then an attending). It has often been shown that patients on Medicaid have worse health outcomes than those on private insurance, though there are likely many factors contributing to this. It is important for these health systems to make every effort to provide the most beneficial treatment to every patient.

On the other hand, academic medical centers offer certain benefits. Residents can be very rich in current knowledge and experience, and studies often show that physicians at academic centers are more likely to follow the most up-to-date treatment recommendations than those in private practice.

✓ 15. **Self-reflection: If you were having surgery, would you allow a resident to assist? What if the patient was your parent? Your child? [35]**

Box 3.6 Case Conclusion

The case of Ms. West that appears above is based on the Wisconsin case of *Johnson v. Kokemoor*, the leading court case ruling that there is an affirmative duty to disclose surgical experience and outcomes [35]. There the patient underwent surgical repair of a basilar bifurcation aneurysm of the brain. Although the clipping of the aneurysm was technically successful, postoperatively the patient lost bowel and bladder control, was unable to walk, was "rendered an incomplete quadriplegic," and suffered other impairments.

In her lawsuit the patient claimed that the surgeon had breached three related duties: (1) to tell her about his experience performing this procedure, (2) to tell her about his morbidity and mortality statistics in comparison to those of other surgeons doing this procedure (sometimes called comparative provider statistics), and (3) to refer her to another hospital with more experienced surgeons.

In the first ruling of its kind, the Wisconsin court agreed on all three points. The core idea in the court's ruling was that this information would be relevant (the law uses the term "material") to a patient's choice of surgeon to repair a basilar bifurcation aneurysm of the brain. Failure to provide this information constituted a failure to respect patient autonomy and violated the patient's right to make an informed choice of surgeon. It was also important in this case that the surgeon had misrepresented his experience, claiming he had done the procedure "dozens" of times, when in fact he had only performed two such aneurysm repairs. This gross and intentional misrepresentation constituted fraud.

The following further summarizes the key ruling in the case:

"[A] patient cannot make an informed, intelligent decision to consent to a physician's suggested treatment unless the physician discloses what is material to the patient's decision, i.e., all of the

viable alternatives and risks of the treatment proposed.' In this case the information regarding a physician's experience in performing a particular procedure, a physician's risk statistics as compared with those of other physicians who perform that procedure, and the availability of other centers and physicians better able to perform that procedure would have facilitated the plaintiff's awareness of 'all of the viable alternatives' available to her and thereby aided her exercise of informed consent. [35]

To more fully bring disclosure of surgical batting averages within the terms of the statute, the court stressed that "When different physicians have substantially different success rates, whether surgery is performed by one rather than another represents a choice between 'alternate, viable medical modes of treatment' under the Wisconsin statute. Surgical experience and outcomes are part of the risk assessment essential to the choice of medical treatment" [35].

References

1. Narins CR, Dozier AM, Ling FS, Zareba W. The influence of public reporting of outcome data on medical decision making by physicians. *Arch Intern Med.* 2005;165(1):83-7.
2. Beauchamp T. Informed consent: its history, meaning, and present challenges. *Camb Q Healthc Ethics.* 2011;20(4):515-24.
3. King JS, Moulton B. Rethinking informed consent: the case for shared medical decision-making. *Am J Law Med.* 2006;32(4):429-501.
4. Sawicki N. Modernizing informed consent: expanding the boundaries of materiality. *Univ of Illinois L Rev.* 2016;821-71.
5. *Estate of William Behringer v The Medical Center at Princeton* [1991] 592 A.2d 1251 (NJ Super).
6. Centers for Disease Control and Prevention. Recommendations for preventing transmission of Human Immunodeficiency Virus and Hepatitis B Virus during exposure-prone invasive procedures [Internet]. Atlanta (GA): CDC; 1991 July 12 [cited 2017 Dec 14]. Available from: www.cdc.gov/mmwr/preview/mmwrhtml/00014845.htm.
7. *Albany Urology Clinic, PC v. Cleveland* [2000] 528 S.E.2d 777 (Ga.).
8. *Moore v. Regents of Univ. of California* [1990] 793 P.2d 179 (Cal.).
9. Centers for Medicare & Medicaid Services. Physician compare initiative [Internet]. Baltimore (MD): CMS. [cited 2018 Jan 15]. Available from: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/physician-compare-initiative/index.html>.
10. Reese S. How will the CMS Physician compare website affect your practice? [Internet]. Medscape; 2013 Nov 15 [cited 2018 Jan 15]. Available from: <https://www.medscape.com/viewarticle/813124>.
11. Dindo D, Demartines N, Clavien P. Classification of surgical complications: a new proposal with evaluation in a cohort of 6336 patients and results of a survey. *Ann Surg.* 2004;240(2):205-13.
12. Maleux G, Koolen M, Heye S. Complications after endovascular aneurysm repair. *Semin Interv Radiol.* 2009;26(1):3-9.
13. Johns Hopkins Medicine. Abdominal aortic aneurysm repair [Internet]. Baltimore (MD); 1991 July 12 [cited 2018 Jan 17]. Available from: https://www.hopkinsmedicine.org/healthlibrary/test_procedures/cardiovascular/abdominal_aortic_aneurysm_repair_92,P08291.