Virtual Mentor
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FROM THE EDITOR

It Takes Two to Make a Relationship

Audiey Kao, MD, PhD

Attendant: The doctor will be with you in a moment.
Elaine: [looking at her chart] Difficult?
Doctor: Elaine, you shouldn't be reading that. So tell me about this rash of yours.
Elaine: Well it's, it's. . . . You know I noticed that somebody wrote in my chart that I was difficult in January of '92 and I have to tell you that I remember that appointment exactly. You see this nurse asked me to put a gown on but there was a mole on my shoulder and I specifically wore a tank top so I wouldn't have to put a gown on. You know they're made of paper.
Doctor: Well that was a long time ago. How about if I just erase it. Now about that rash. . .
Elaine: But it was in pen. You fake erased.
Doctor: All right Ms. Benes. This doesn't look too serious. You'll be fi**ne.**
Elaine: What are you writing? Doctor. . . .

In this classic *Seinfeld* episode, Elaine Benes learns that she was once labeled a "difficult" patient because she wouldn't cooperate with a nurse and change into a paper examination gown. Subsequently, Ms. Benes encounters problems getting necessary treatment for her rash and believes it is because physicians consider her to be a whiner and malingerer. Ms. Benes resorts to stealing her medical chart in an effort to erase this label, which only adds to further chart entries and a spreading reputation of being difficult that sticks to her like the rash that plagues her.

What do we mean when we say that a patient is difficult? To some, a difficult patient is one who makes irrational choices that would be harmful to his or her own health. Others may see a patient who engages in disruptive conduct as difficult. In some circumstances, it may boil down to a clash of personalities between a patient and physician. At other times, the difficulties arise as a result of something more fundamental such as patients' beliefs and values that run counter to the physician's own. Generally, patients are considered to be difficult when their decision-making, behavior, personality, or beliefs impede the provision of good medical care.

I doubt that there is a practicing physician among us who has not dreaded seeing the name of a particular patient on his or her appointment list. This dread is shaped in part by biases that range from patient features as seemingly basic as body hygiene to those as substantial as religious convictions. In between is an entire range of personality traits—demanding, unpleasant, bigoted—that may test the patient-physician relationship.

Like agents in any other social relationship, patients and physicians will sometimes have difficulty establishing rapport—a physician simply dislikes a patient (or vice

versa). Demanding and complaining patients challenge physicians' ability to respond compassionately and to ignore the behaviors that they find offensive. In such situations, it is critical for the physician to determine that the annoying behaviors chalked up to "personality" are not actually reflecting unmet patient needs. If the behavior is related to need, the physician has a professional obligation to deal with that need without discriminating against the patient. Hateful and bigoted patients, on the other hand, severely test a physician's objectivity and sense of justice. In these situations, there are no easy remedies, particularly in a medical emergency or when patients' access to other sources of care is limited or non-existent.

The characterization that good care cannot be properly dispensed because of difficulties arising solely from patients' beliefs and behavior fails to capture the relational complexity of interactions among patient, physician, and context just discussed. As physicians, we recognize that difficulties in the clinical encounter come with the territory, and that some challenging situations are never going to be adequately resolved. At the same time, I firmly believe that the desire to help people, even those they may disagree with or dislike, continues to motivate individuals who choose to pursue medicine as a career. In this spirit of realistic idealism, this theme issue of the Virtual Mentor explores the ramifications and remedies of the difficult patient-physician relationship. It is our hope and expectation that the featured stories, analyses, and subsequent online discussions will provide our readers with insight and information on how to better deal with the difficult situations that invariably arise when patients and physicians interact.

Audiey Kao, MD, PhD is editor in chief of *Virtual Mentor*.

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CASE AND COMMENTARY
Obligations to Noncompliant Patients
Commentary by Faith Lagay, PhD

Case
After treating 19-year-old David E. for chronic renal failure for several years, nephrologist Dr. T. became exasperated and told David he wished to terminate the therapeutic relationship because of David's abuse of alcohol, failure to take his prescribed medication, frequently missed hemodialysis appointments, and repeatedly disruptive behavior in the clinic when he did show up for treatment.

David E. sought a court order to block Dr. T's termination of the relationship, in essence, an order compelling Dr. T to provide treatment including the necessary hemodialysis. Noting that physicians are free to choose whom to serve and that hospitals can only be compelled to treat in cases of medical emergency and active labor, the court ruled that Dr. T. could terminate the relationship and that the hospital was not required to offer David E. hemodialysis if he continued his disruptive and non-compliant behavior.

David E. lived in a mid-sized city, and word of his case spread among the medical community so that is was difficult for him to find a physician and hospital for his required treatment. He appealed the court's decision. On appeal, Mr. E's attorney claimed that his chronic physical illness resulted in severe depression that constituted a psychiatric disorder, and that this psychiatric disorder was the cause of Mr. E's non-compliance and disruptive conduct.

The Americans with Disabilities Act (ADA) of 1990 defines psychiatric illness as a disability. Mr. E's attorney argued that to deny David E. treatment because of his non-compliance would be denial based on a psychiatric illness or disability, a denial prohibited by ADA.

Questions for Discussion
1. Does the cause of David E's conduct—psychiatric illness versus a rational decision that the medical restrictions are not worth the trade off—alter Dr. T's ethical obligation to his patient?
2. If the appeals court, considering the ADA defense, orders Dr. T. to treat David E, will that decision violate the physician's freedom to choose whom to serve?
3. Is chronic need for life sustaining medical treatment (e.g., hemodialysis) the same as emergency need? Do laws and policies that compel physicians and

hospitals to provide emergency care encourage patients with chronic illness to let their conditions reach acute crises in order to get care on demand?

Faith Lagay, PhD is managing editor of *Virtual Mentor*.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

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IN THE LITERATURE

Physicians' Responsibility in the Face of Patients' Irrational Decisions

Faith Lagay, PhD

Brock DW, Wartman SA. When competent patients make irrational choices. *N Engl J Med*. 1990;322(22):1595-1599.

As more value is placed on the patient-physician partnership and joint decision-making, physicians increasingly face the dilemma of how to respond to patients' treatment choices that appear irrational. In a 1990 Sounding Board article for *New England Journal of Medicine*, a bioethicist and physician explore the dilemma in a way that has retained its currency and offers practical suggestions for today's clinicians. Dan Brock's and Steven Wartman's "When Competent Patients Make Irrational Choices" discusses (as their title makes clear) only decisions of *competent* patients whose request for or refusal of treatment appears to frustrate their own medical goals[1].

An "irrational" decision, Brock and Wartman say, is one that satisfies the patient's "aims and values less completely than other available choices"[2]. So, for example, a patient who wishes to go on living a healthy, productive life yet refuses a life-saving intervention has made an irrational choice in the context of his or her own values and future plans. The authors present a taxonomy of irrational choices and their causes. (1) It is irrational, they say, to bias one's decision toward the present and near future, e.g., to refuse to undergo a painful experience now if it will prevent a much worse experience in the future. (2) A second source of irrational decisions is the believe that a given unwanted outcome "won't happen to me." Here patients might be denying the risk (as invulnerable adolescents might); acknowledging the risk but deciding to take the odds; entertaining magical beliefs about the situation; or simply viewing the medical problem in a different way. It is important for physicians to distinguish among the causes for "it won't happen to me" decisions, because they may be able to help the patient understand the risk more realistically or might need to see that the patient gets counseling or psychiatric evaluation. (3) Patients frequently refuse or delay a diagnostic procedure because they fear it will uncover a dreaded disease; they refuse or delay treatment because they fear the experience—being put to sleep, being cut open. To assist such patients, physicians should respect the value they place on avoiding pain and suffering while helping them overcome unrealistic fear that prevents them from consenting to beneficial treatment. (4) A most troubling instance for physicians occurs when patients make choices that just don't make sense. If a decision of this type accords with a well recognized though unusual belief or cultural value (e.g., no blood transfusions),

physicians generally respect it. When the decision is not attributable to a religious belief or cultural value, the physician should try to determine whether it is, nevertheless, a strongly held value or a "distortion of values caused by a treatable condition such as depression"[3].

Physicians might unwittingly contribute to irrational decision making by the way they frame choices. The authors suggest, for example, that risk of loss "looms larger" than possibility of gain in decision-making. Understanding irrational decisions and their causes is important because physicians must decide when to accept patients' decisions—even those that seem not to be in their best medical interest—and when to try to persuade patients to change them. While physicians have a responsibility to try to change the irrational decisions of competent patients, in the end, such decisions must be respected if the patient is competent and cannot be persuaded non-coercively to change them.

Questions for Discussion

1. Do you agree with the authors that, as long as patients are competent, all of their decisions, even irrational ones, must in the end be respected? Are there situations in which a physician can override a competent patient's irrational decision?
2. Does the physician have any responsibility for the patient after attempting and failing to persuade him or her to accept treatment that is in his or her best medical interest? When the patient remains firm in his or her decision, what can or should the physician do next?

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AMA CODE SAYS
Right to Choose Patients and Duty Not to Neglect
Faith Lagay, PhD

The AMA *Code of Medical Ethics* currently has 2 opinions that relate to initiating and terminating the patient-physician relationship. Opinion 8.11 entitled 'Neglect of Patient' actually begins by acknowledging that physicians are free to choose whom they will serve. It then states that physicians should respond to the best of their ability in emergencies and that, "once having undertaken a case, the physician should not neglect the patient." Opinion 8.115, 'Termination of the Physician-Patient Relationship,' grants that physicians have the option to withdraw from the relationship, but may do so only after "giving notice to the patient, the relatives, or responsible friends sufficiently long in advance of withdrawal to permit another physician to be secured."

These 2 notions—that physicians can choose whom to serve and can terminate the relationship—first entered the *Code* in 1912, 65 years into its history. Prior to that, the *Code* warned only—and eloquently—against abandoning patients. The first *Code*, written at the time of the association's founding in 1847, put it this way:

> A physician ought not to abandon a patient because the case is deemed incurable; for his attendance may continue to be highly useful to the patient, and comforting to the relatives around him, even to the last period of a fatal malady, by alleviating pain and other symptoms, and by soothing mental anguish. To decline attendance, under such circumstances, would be sacrificing to fanciful delicacy and mistaken liberality, that moral duty, which is independent of, and far superior to all pecuniary consideration[1].

In discussing non-abandonment only in relation to patients with incurable conditions, the *Code* followed the age-old Hippocratic standards for physician conduct. It is possible that the Hippocratic proscription on abandonment was necessary because physicians, eager to protect their reputations as healers, might avoid patients who were hopelessly ill. There is clear concern in Hippocrates, says Dr. Edmund Pellegrino, for the physician's reputation if the patient were to die[2]. The *Code's* mention of "pecuniary consideration" lends credence to the interpretation that, even in 1847, physicians might fear the consequences that losing a patient could have on their reputation and future case load (Dr. Pellegrino adds that the Hippocratic concern for reputation may have been a warning to prognosticate accurately.)

In any case, the warning remained about the same when the *Code* was revised in 1903. The second sentence with its flowery appeal to moral duty was deleted; the

"physician " in the first sentence became "the medical attendant," and the item gained a title: "Incurable Cases Not To Be Neglected."

When the *Code* was next revised in 1912, a new concept entered the discussion of patient non-abandonment. Now titled "Patients Must Not Be Neglected," the principle introduced the idea that, except in emergency situations, the physician is "free to choose whom he will serve"[3]. The paragraph then goes on to say that, "once having undertaken a case, the physician should not abandon or neglect the patient because the disease is deemed incurable." The paragraph ends by pointing out the responsibility that is complementary to the freedom of choice just granted: once having undertaken a case, the physician should not withdraw for any reason "until a sufficient notice of a desire to be released has been given the patient or his friends to make it possible for them to secure another medical attendant"[3].

Two changes are notable here. First, there is recognition that physicians might wish to sever relationships with patients for reasons other than the patient's incurable illness. The second notion, that physicians have the freedom to choose their patients, except in cases of emergency need, is elaborated upon in a small pamphlet published by the AMA in 1936 entitled *Economics and the Ethics of Medicine*[4]. Physicians' right to choose patients, the pamphlet explains, is merely the counterpart to the patients' right to choose their physicians. Moreover, this right sets physicians apart from the economic and legal class of the "'common carrier,' such as a railroad or an express company."

In the major revision of 1957, the *Code's* 8 chapters with their 48 sections were replaced by 10 principles that summarized the fundamental concepts of the earlier *Code* but omitted the time-sensitive specifics that could easily become outdated. In the 1957 principles, the choice to treat / non-abandonment topic became principle number 5:

> A physician may choose whom he will serve. In an emergency, however, he should render service to the best of his ability. Having undertaken the care of a patient, he may not neglect him; and unless he has been discharged he may discontinue his services only after giving adequate notice. He should not solicit patents[5].

Incurable disease had disappeared altogether as a reason for neglecting patients. (The prohibition on soliciting patients that was tacked on to principle 5 had a former life as a stand-alone section entitled "Advertising." The section condemned solicitation of patients as unethical. "Self laudations defy the traditions and lower the moral standard of the medical profession: they are an infraction of good taste and are disapproved"[6]. By 1966, the topic of advertising had been restored to a section of its own.) The language of patient non-abandonment remained unaltered (though its titled changed from "Patient Must Not Be Neglected" to "Neglect of Patient" until 1996 when the Council for Ethical and Judicial Affairs decided to split the opinion into 2: "Neglect of Patient" and "Termination of the Physician-Patient Relationship, which is how the *Code* reads today."

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PERSONAL NARRATIVE

"Hey Daktari, Will You Sign This?"

Robert Davidson, MD, MPH

My relationship with the Peace Corps volunteers in 5 countries in Eastern Africa is different from any of my previous experiences with patients. For the most part, it is satisfying; its challenges principally clinical. As in any situation, however, occasional difficulties of a more personal type arise. Several aspects unique to working for the US government in Eastern Africa lend themselves to potential problems: the closeness of the community, the level of stress and fear in the volunteers, and the potentially conflicting expectations of the various roles I have as physician to this special community.

The volunteer experience is an intense one. Each country has approximately 150 volunteers who spend 2 to 3 years “in country.” Their dependence on Peace Corps staff leads to very close relationships. Volunteers often stay at my house when they are in Nairobi. Some have difficulty making the transition from this friendship to a patient-physician relationship. For example, although I am very comfortable being called by my first name, as is the norm with other staff, most volunteers prefer to call me "Doc," "Dr. D.," "Daktari," or some variation. When the volunteers get together in the evening, the staff is usually invited. When I attend, I sense that I become a damper on the festivities, especially on the amount of alcohol consumed. This may not be a bad thing. It is likely that my presence reminds them of my in-training exhortations regarding all kinds of health risks, including the use of excess alcohol. It is clear that the volunteers want a certain distance from "their" physician, partially because I will soon be doing their testicular exams or Pap smears, but there is more to it than that. Maintaining a certain professional relationship helps sustain my role as their health advisor and, in many respects, as their "parent in absentia." Most of the volunteers are about the age of my 3 sons, and I am comfortable with this role. I have just never experienced it before in my professional career.

I have often used the analogy of a "stress test" for the Peace Corps volunteer experience. I tell the volunteers that just as we exercise a patient to look for any evidence of cardiac ischemia, they are undergoing a two-year life stress test. It is quite understandable that health or behavioral issues, easily kept at an acceptable level in their previous life, manifest as problems in Africa. I also tell them that the coping skills they develop during this experience will be of tremendous value to them the rest of their lives.

Relatively minor symptoms can become exceedingly frightening when you are living 50 kilometers from the nearest village with a phone and 2 days travel time from competent medical care. When they do come to the medical unit, a thorough exam and use of appropriate diagnostic tools usually allow me to reassure them of the benign nature of their symptoms. However, some are convinced that their symptoms indicate an undiagnosed tropical illnesses. For example, one young man experienced total temporary paralysis while lying in bed at his site. Though the neurologic exam was normal, he was certain that he had some tropical illness and was frightened to return to his remote village. When I cannot find a cause for the volunteer's symptoms and begin talking about how to cope with the problem, I often sense a feeling of skepticism. "Look Doc. This isn't stress. My hair is falling out." "You mean to tell me that I have not had a menstrual period for 6 months because of stress?" "So what if the 10 stool examinations you've done show no parasites, Doc, I know this cramping is not related to stress. This is not the irritable bowel syndrome I had in college."

Occasionally, the roles of physician-as-clinician and physician-as-administrator come into conflict of what I call the “company doctor” type. Reimbursement for travel presents one such potential conflict. A volunteer comes to Nairobi for a presumed medical visit. After a normal exam and very little evidence of any problem, I am presented with a form to authorize reimbursement to the volunteer for travel to Nairobi, hotel charges, and per diem. "Hey Daktari. Will you sign this?" Usually we can negotiate this. Occasionally, the request for signature comes after one of the nurse Peace Corps Medical Officers has already seen the volunteer. I suspect that the old shuffle is occurring. If you do not like the response from one person, you go to another hoping for a different, more favorable reply. How well I remember this ploy as our sons were growing up.

The most difficult challenges surround the fundamental ethic of physician confidentiality. The role conflict arises when I learn, as part of a medical interview, that the volunteer is engaging in behavior that puts him or her at too high a health risk in Africa. An example might be repeated episodes of refusing to use safe sex practices with multiple partners. The HIV risk in the Eastern African countries is far too high for me to allow this type of risky behavior to continue. When I become aware of this behavior, it is incumbent upon me to initiate procedures for the volunteer's separation from the Peace Corps. Another example entails the Peace Corps' zero-tolerance policy on the use of illicit drugs. The risk to the volunteer from the drugs is made all the greater by stringent in-country laws against illegal drugs: the standard jail term for possession of illegal drugs in Kenya is 10 years. On the one hand, I try to foster a relationship of trust with the volunteer that includes confidentiality regarding information given in the course of a visit. On the other hand, I have a clear moral obligation to do the "right" thing for the volunteer even if he or she is unhappy about it. I also must honor the agreement I made with the US government when I was hired to adhere to the regulations of the agency. Informing volunteers of the limits to confidentiality is part of the Peace Corps orientation

process. They are informed that non-disclosure of a significant health problem is grounds for dismissal.

I am glad that we did not title this month's theme the "difficult patient." The patients are not difficult. There are just some difficult issues that arise in the course of providing care to this unique group. Perhaps the issues I am facing are no different from those in any patient-physician population. However, they sure seem different, more common, and more troubling here in Eastern Africa.

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PERSONAL NARRATIVE

Through the Physician's Eyes: Difficult Patient-Physician Encounters in the Emergency Department

Faith Lagay, PhD and Art Derse, MD, JD

There's a good reason—many, in fact—that the television drama "ER" has been a runaway hit for 8 years. The emergency room is a crucible for the medical encounter. Life-threatening illness and trauma are more likely to appear here than in the office or clinic, hence, decisions often must be made quickly. Patients' physical distress and fear push them to extremes of behavior. Crisis, fear, strange behavior, and the opportunity for heroic success or failure—the elements on which drama and melodrama thrive—are commonplace in the emergency room or emergency "department," as the expanded service in most hospitals is now more properly known.

It makes sense that these high-pressure conditions turn up the heat on the patient-physician interaction also. The personalities of individual patient and physician and the range of personal, social, and professional expectations that each brings to the interaction always have the potential to turn the medical encounter into a difficult one; they are almost certain to do so in the emergency department where patients are frequently hostile, angry, combative, or abusive if special care is not taken to avoid potential problems. Examining the conditions at work in difficult emergency department encounters yields the rewards of studying any "worst case": the examination reveals signs that might be present but overlooked in less exaggerated or pressured encounters.

Characteristics of the Emergency Department Encounter

Several characteristic features of the emergency department encounter combine to create the potential for very difficult patient-physician interactions.

1. Perhaps the most consequential characteristic is that the patient who walks or is brought into the emergency department and the physician who is there to treat that patient are generally meeting each other for the first time. There is no prior relationship and no patient history to refer to. Neither party knows what to expect and either or both may be suspicious. Incidentally (some would say "unfortunately") some office and clinic visits these days are coming to resemble emergency room visits in this regard more closely than they resemble office visits of the fee-for-service days. That is, more patients are seen by practitioners who do not know them and who may or may not have a written or online history available. Thus, knowing what

makes for troublesome emergency room encounters and how to diffuse them may have broader application in today's managed care system than it had in the past.

2. The emergency department is frequently the "re-entry" point for patients who have severed themselves from a patient-physician relationship and from routine medical care. Not only is the patient unfamiliar to the physician, but members of this patient group may also be non-compliant, perhaps because of psychiatric illness or distress, perhaps because of substance dependence, denial, or inability to pay for routine medical care and prescription drugs. When acute illness or injury eclipses the reason for the patient's neglect of proper medical care, he or she presents in the emergency department, often with many slight to severe, untreated health problems.
3. Patients may have been brought to the hospital against their wishes, by friends, family members, an emergency response team, or police. If so, they may be hostile, combative, or abusive and attempt to refuse treatment or to leave the hospital.
4. Some of those whose only medical care comes through the emergency department are homeless or otherwise outside the community's safety nets of care. These patients, whose numbers are greater in urban areas, may have become dependent upon street survival behaviors that don't rely on the open exchanges of information and discourse expected in the patient-physician relationship. Their unkempt appearance and lack of manners may be off-putting to the clinician.
5. Ethnic, cultural, and language differences may present barriers to good communication.
6. Finally, even those patients who receive routine medical attention, have no psychiatric diagnosis, are compliant, and may be meeting their own primary care physicians in the emergency department are in some physical or psychological distress or they wouldn't be seeking medical care. They are often upset, perhaps fearful, and maybe unable to process information in their characteristic rational manner.

Managing Difficult Emergency Department Encounters

Emergency physicians cannot anticipate that all encounters will unfold according to the standard expectations for successful patient-physician relations, that is, that privacy and confidentiality will be maintained and patient autonomy exercised. Any of the typical emergency department characteristics described above can frustrate these ends. Privacy, autonomy, even assessing and addressing the medical complaint itself are often not the emergency physician's first priority in managing uncooperative patients.

To begin with, the physician should see the patient in or near the presence of others, not in private where there may be physical danger. In most emergency departments aides or security personnel are available to assist if the patient becomes unruly. Those not involved in the patient's care (hospital security personnel or police

officers) should be discretely placed so that the patient is aware that they are present or nearby, but they should not intrude on the patient-physician encounter unless they are actively engaged in guarding or controlling the patient.

The physician's first intervention is to assure the patient in a non-threatening way that, regardless of the circumstances, his or her health is the physician's primary concern. Often physicians must maintain control of their own emotions, responding to patient anger and even abuse calmly and undefensively.

It is difficult to list what goes on next in sequence. The physician must determine, almost simultaneously:

- Whether the patient is likely to pose a threat of harm to him- or herself or to others.
- Whether or not a medical emergency or need exists? Whether the patient is in physical distress? Intoxicated? Psychotic? Attempting to get a prescription for narcotics?
- Whether the patient is competent to accept or refuse treatment? If not, whether someone is present who can speak as the patient's surrogate?

The possible combinations of answers to these questions determine how the encounter proceeds. If a medical need is present and the patient is not combative or hostile and is competent to discuss and consent to or refuse treatment, the encounter resembles a traditional acute medical intervention. If medical need is present and the patient Is highly combative or frenzied, with frankly compromised mental status, he or she can be restrained or sedated so that the need can be assessed and treatment can proceed. The physician may ask security personnel or police to detain or control the patient.

The situation is far trickier when the patient is in such emotional or psychological turmoil that medical need cannot be easily ascertained and when competency is not easy to determine. Suppose the patient is intoxicated and resisting attempts at diagnosis. Most people with a .10 percent blood alcohol level are competent to weigh the risks and benefits of proposed medical interventions. Most people with .20 percent blood alcohol levels are not. The blood alcohol level at which competency is compromised differs from individual to individual, so the physician must make a judgment and proceed, knowing that the judgment could be contested by the patient or others at any point during that long period of calm and hindsight that follows the emergency.

The general guideline for determining decision-making competency is the computer model. Patients should be able to "take in," "analyze and measure," and "give back" information. In this case "take in" is shorthand for understanding the facts of one's medical condition, its consequence if left untreated, and the nature and risks of treatment options. "Analyzing and measuring" means that the patient can weigh the risks and benefits of proposed treatments and their probable outcomes and can

measure those risks and benefits against an internal set of values and future goals. The competent patient then arrives at a decision and can "give back" that information in a consistent way, that is, not changing the decision each time it is stated. The decision should make sense relative to his or her values. Refusing surgery because it is frightening, for example, may be perfectly reasonable but not consistent with a goal of continued life. Obviously, the need to feel secure about the patient's competency increases as the risk associated with an intervention or the refusal of an intervention increases. A psychiatric consult may be needed. In all events, seriously injured or ill patients who refuse treatment should be given comfort care rather than turned away because of their refusal[1]. As the distress from the injury or illness increases, and with continued encouragement of medical staff, they may change their decisions.

Conclusion

The majority of emergency department encounters never become difficult enough to warrant intervention from security staff or police. Nothing is lost, however, in the brief period of time taken to approach the unknown patient with calm reassurances, in the presence of others who may need to assist the physician, and to determine whether emergent or urgent medical need is present. On the other hand, questions regarding patients' competency to consent to or refuse treatment commonly arise in the emergency department.

Given the likely physical and emotional distress of patients with emergency medical needs, their possible estrangement from routine health maintenance, and the diverse psychosocial and cultural backgrounds and expectations that converge in the emergency department, it's small wonder that the real life "ER" offers an intense immersion course in managing difficult clinical encounters.

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PERSONAL NARRATIVE

Through the Physician's Eyes: The Racist Parent

William McDade, MD, PhD

The woman was from northern Indiana and had come to our regional medical center heralded for its expertise in pediatric medicine. Her child was not doing well and she wanted the best. Further, she was willing to travel into a neighborhood very much different from her own to insure this expertise. On morning pre-rounds, the African American fourth-year medical student entered the infant's room and was confronted by the child's mother who inquired and then accused. The medical student explained her role was to examine the child and to learn what had transpired in his health care overnight. She stated that she was a part of a larger team that included the internationally famous attending physician who was leading the teaching effort. This was unfortunately not sufficient for the mother's satisfaction.

She stated that she did not want any of "your kind" touching her child. She elaborated further that anyone who had been granted admission into medical school through affirmative action should not be there, and that no recipient of societal welfare is going to touch her sick child. The student was aghast. Hurt, anger, doubt, and frustration intermingled within her. She was devastated and now tearfully left the patient's room. I am not sure what must have been going through the mother's mind at that time. Did she feel that she had successfully protected her child from some assault from a poorly educated black woman? Did she feel that the debased medical student would suddenly come to her senses give up her study of medicine through such harshly delivered discouragement? Did she feel good about herself for having made another human being of a different race feel bad?

The medical student, who was a hard-working scholar and researcher, had performed wonderfully during her 4 years of medical school. Her top university had historically accepted few African American students per class, and there were vanishingly few minority faculty despite the fact that the medical center was in a predominantly minority community. Most of the hospital staff were African American as were the vast majority of the patients. In fact, this mother was seeking to establish a protective circle of whiteness in a sea of cultural difference. The reality was that there was no affirmative action program in place at the medical school and that the student's scores and undergraduate performance allowed her to select from multiple offers of acceptance from medical schools. She had done research as an undergraduate and spent all of her summers prior to medical school engaged in a scholarly endeavor. She was a person of diminutive stature and quiet unassuming personality. She enjoyed her experience in pediatrics so much as a third

year medical student that she elected to do a subinternship in pediatrics as a fourth year and was ranked among the better students in her cohort. Her goal was to train to become a pediatric intensivist.

The student immediately reported the events of the early morning to her senior resident and asked what she should do for resident rounds. Her older colleague suggested that she should describe the situation for the attending physician during teaching rounds and ask what she should do. Meanwhile, the remainder of the team, excluding its only African American, would examine the child during work rounds and prepare the progress note. They would also arrange a change in coverage so that the intern would handle that patient as opposed to the original distribution of patients. After all, who would want to serve a patient who insulted them so?

Life in a teaching hospital is often complicated by requests from patients who ask for the most senior person on the team to do the procedure or examination; but, most understand that the presence of medical students and residents is part of the package in coming to the university system for care. History-taking and relatively non-invasive physical exams are generally well-tolerated for the relative inconvenience they bring to the inpatient experience. Some rightly think that the more minds weighing in on their problem, the better; and many enjoy the chance to help train the nation's emerging physician workforce. It did not appear that the mother had a problem with the teaching hospital concept, because she did not prevent other physicians-in-training from examining her child. It was clear that the single overriding issue was race alone. Cultural intolerance was afoot here. During teaching rounds the situation was detailed for the attending physician.

What were the options for the attending? If she honored the patient's mother's wish, she would have to exclude the fourth-year medical student from the team when examining and discussing this patient. If she invited the African American student into the room with the team and insisted that the student be the primary contact with the parent as had been her original assignment, she would run the risk of negating the parent's request. A final option would be to explain the nature of the teaching hospital and the attending physician's responsibility to educate tuition-paying students, and to offer to help the mother secure care at a different institution. Counterbalancing these options were: the financial incentive the attending had for caring for a well-insured patient; the potential referral pattern that might be disrupted if an unsatisfied patient complained to her referring physician about her preference rejection; and the desire to give a fearful mother comfort during the stressful period of her child's illness.

So, what would you have done as the attending physician? How would you have helped the fourth-year student deal with the doubt, rejection and humiliation she experienced? How could you use this experience to demonstrate the impact of cultural intolerance to the other residents and students on the team? How would you have comforted the parent and ensured patient satisfaction?

In this case, the attending physician chose to ask the fourth-year medical student to remain in the hallway while the rest of the team examined and discussed the patient's progress. The budding pediatric intensivist was completely devastated and sought recourse through the medical school. Fortunately, the situation was short-lived and the patient was soon discharged; however, the damage had been done. The humiliation, alienation, and pain were too intense for the student. In selecting a residency program, these events weighed heavily and caused the student to bypass her own university in the residency matching process. She is now successfully completing her pediatrics residency elsewhere. However, what message was transmitted to her colleagues in training through their observations of their colleague's treatment? Will they perpetuate the behavior exhibited by their teaching-attending physician or will they learn the irrationality and pain associated with racism and act to confront it in their future?

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PERSONAL NARRATIVE

Through the Patient's Eyes: Conversation with a Famous Patient

Kayhan Parsi, JD, PhD

An interview with Dax Cowart, who became the poster child for a patient's right to refuse treatment when he suffered severe burns as a young man, discusses the importance of good communication skills in the patient-physician relationship.

Patients often don't challenge physicians because they think that being labeled "difficult" will affect their care. Do you think this is true?
Yes. Patients wonder, "Am I going to say something and get the doctor angry with me?" They understand that a doctor may be technically fine, but if you disagree or challenge him, you might not get the best care. Then you're stuck with a bad relationship with your doctor. You don't need to deal with a person who is cold and distant.

We usually place ethical duties on physicians. Do patients have any duties when it comes to their care?
Both the patient and the physician have the responsibility to share information in language the other can understand. Doctors frequently use medical lingo that patients can't understand. Patients have a responsibility to listen to and respond to the physician. Certainly, a patient has the right to be non-compliant, but then the physician should find out why is the patient being non-compliant. You ought to be able to be non-compliant and still receive care. That's what respect for patient autonomy means. If a doctor provides meaningful information that the patient understands and the patient is still non-compliant, that is not a valid reason for the physician to lessen the quality of care.

Has patient autonomy improved in the last 25 years?
It has and it hasn't. Advance directives are still often ignored. Patients are still frequently not giving anything that resembles informed consent, and informed consent is the cornerstone of patient autonomy.

What do you think of waiver of informed consent with regards to autonomy?
In a way, it is respecting a person's autonomy if that person wishes to waive the right to receive information and to consent or refuse, as long as the waiver is not irrevocable. The prudent thing to do, once the doctor knows something about the patient based on the medical record or chart (and the patient has some serious illness), is for the doctor to tell the patient that sometimes he will have good news to report and sometimes he will have bad news to report, and he doesn't know what

it will be. He can tell the patient, "looks like you had some bad heart attacks. Do you want me to disclose everything or not?" The answer will vary from patient to patient. My grandmother, for example, did not want to be told everything about her illness.

Often, a patient chooses a lifestyle (such as smoking or being sedentary) that contributes to a difficult care situation. Do patients have a duty to change their lifestyles?
I don't think it's easy for patients to change their lifestyles. I'd say, go ahead and find your overweight doctors and those who smoke; they're the most understanding. Doctors don't frequently provide support. I'm disturbed by the lack of support among doctors for preventive care. I heard Andrew Weil say something to the effect that whenever he brought up preventive care, his classmates and professors looked at him as if he were from another planet. We spend gazillions of dollars on curing but not enough on prevention.

What should doctors do then?
In general, doctors have a strong tendency to do all the talking and very little listening. As a lawyer, you have to listen to the facts; doctors should do the same thing. Patients who persist in wanting more time to explain what's wrong are often called whiners.

Let's talk about the lawyer-client relationship. Have you ever dealt with a difficult client?
I sure have! (*laughs*) You tell clients what you need and they just don't do it. Non-compliance, right? Sometimes there are terrible attitude problems, but often the cause is the same as with patients and physicians—a lot of lawyers don't spend enough time with their clients. They need to be professional enough to find out what's causing the difficulty. The number 1 complaint among clients is that lawyers do not return phone calls. Law and medicine are not assembly line processes. The doctor may get the patient well and the lawyer may win the trial, but more attention should be spent on nurturing the relationship to improve the likelihood of a good outcome.

So the bottom line to the patient-physician relationship or the lawyer-client relationship is nurturing a good relationship?
A good model for doctors and lawyers are well trained chaplains. I've seen quite a few of them—chaplains will to go to the patient and listen. They say, "I'd like to help you." They're trained in the art of listening. They don't come in and try to proselytize or have an agenda. We cannot be good doctors or good lawyers if we're not good listeners.

Do you have any recent experiences that shed light on this issue?
Yes. I went to see a few doctors because I believed I had CFS (Chronic Fatigue Syndrome). I had a whole list of symptoms, but all but 2 doctors would just glance at my list. They weren't listening to what I was telling them and taking it into

consideration. They were already on their own path as to what was wrong and were not interested in the symptoms I was experiencing. They tried to attribute the symptoms to depression or insomnia and things like that. On the other hand, one doctor listened and did an excellent job. Similarly, right after my accident, I was seen by a doctor at Parkland about the best way to treat my eyesight and prevent infection. He gave me a choice. There were 2 options—he could shut my eyelids or leave them open. I asked him which would give me better odds for vision. He said sewing them shut. He didn't come in like a computer, but was attentive and caring.

Any parting thoughts?
Time after time, physicians are shocked when they become patients. Perhaps if every 6 months doctors and patients could reverse roles it would allow doctors to better understand what it means to be a patient.

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PERSONAL NARRATIVE

Through the Physician's Eyes: If One More Doctor Tells Me I'm Crazy, I'm Going to Go Postal

Matthew Wynia, MD, MPH

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

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

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

"How long has this been going on?" At least a year, probably more, she says. Examining her, it looks like it. Her skin is red and patchy, with scabs, scars, and open lesions virtually everywhere she can reach. Areas of skin that are readily accessible for scratching, such as her forearms, neck, scalp, and lower legs, have bloody and crusting sores, some of which appear to have developed mild superficial skin infections. She is anxious to show me her scalp, which has born the worst of her exuberant scratching. Large patches of hair have been torn out, replaced by weeping scabs. Her skin is dry from over-washing, scratching, scraping, and using alcohol swabs in attempts at disinfection. But there are no parasites. No creeping creatures, no mites, no fleas, no bites, no pustules with worms poking their nasty heads out. Her laboratory tests are normal. There are no parasites in her stool.

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

Sometimes it is treatable with anti-psychotic medications. But many patients with delusions of parasitic infestations will refuse psychiatric care, believing that this won't help cure their infestation. She, for instance, cannot conceive of the possibility that she is not infested.

So I tell her that I don't know the exact cause of all of her symptoms, but that scratching her sores will not help and that I do not know of any antibiotic that will help either. Perhaps some medicine to reduce her itching. Some skin creams to use when she feels like scratching.

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

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

I know the diagnosis—but I don't tell her. I will tell her psychiatrist instead.

"Therapeutic privilege," you see. It is the professional privilege that allows physicians to withhold information from a patient when I believe the information might harm the patient.

Though I still wonder whether I did the right thing, I console myself in the fact that she made it relatively easy to withhold her diagnosis. After all, I certainly didn't want her to go postal.

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VIEWPOINT
The Difficult Appendage
Audiey Kao, MD, PhD

Did you know that...

- Robert Smith, a surgeon at Falkirk and District Royal Infirmary in Scotland, amputated the legs of two patients. Stories about amputations are generally not newsworthy, but in this case there was no medical reason for the amputations except that the patients' requested the body-altering operations. Dr. Smith and the psychiatric consultants who reviewed these difficult cases concluded that the amputations were justified because other options were ineffectual and self-induced amputations could have proved fatal for these patients. There were plans to carry out a third amputation when the new hospital oversight committee rejected further patient-requested amputations[1].
- Individuals who request elective amputation of otherwise healthy and non-deformed limbs are believed to suffer from apotemnophilia. In 1977, the Johns Hopkins psychologist John Money published the first modern case history of apotemnophilia—an attraction to the idea of being an amputee. It is considered to be part of a group of psychosexual disorders called paraphilias, often referred to as perversions by the lay public. However, very few articles have been published[2, 3] on this disorder, and not much is known about its pathophysiology and treatment. Some consider these patient requests to be no different than that which motivates inappropriate cosmetic surgery based on a pathology in body image, while others view these amputations as invasive psychiatric treatment.
- Michael First, a psychiatrist at Columbia University, who was the editor of the 4th edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) of Mental Disorders, is undertaking a study that will help determine whether apotemnophilia should be included in the 5th edition of the DSM. If apotemnophilia is included, assessing whether amputations are an appropriate treatment for this mental disorder will pose some unusual dilemmas for potential investigators and members of institutional review boards.
- The 2 patients who requested and received amputations performed by Dr. Smith have voiced great satisfaction and relief that now they feel complete without 4 limbs.

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