

Virtual Mentor

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The Difficult Patient-Physician Relationship

From the Editor

- The Difficult Patient-Physician Relationship** 113
Audiey Kao, MD, PhD

Case and Commentary

- The Patient-Parent-Physician Relationship, Commentary 1** 115
Commentary by Art Elster, MD
- The Patient-Parent-Physician Relationship, Commentary 2** 119
Commentary by Patrick Staunton, MD
- When a Nonadherent Patient Needs Your Care** 122
Commentary by David A. Bennahum, MD
- Never Symptom-Free** 125
Commentary by Griffin Trotter, MD, PhD
- When Disability Is in Question** 129
Commentary by Guy Micco, MD

In the Literature

- Physicians' Responsibilities in the Face of Patients' Irrational Decisions** 133
Faith Lagay, PhD
- Who Is Being Difficult? Addressing the Determinants of Difficult Patient
Physician Relationships** 135
Michelle Lim

Health Law

- Can Patients Contribute to Medical Negligence?** 138
Lisa Panique

State of the Art and Science

Wilson's Disease: Diagnosis and Treatment	141
Audiey Kao, MD, PhD	

Policy Forum

A Responsible Patient	144
Swathi Arekapudi	

Personal Narrative

Midnight Encounters	148
Gary Fontan, MD	

Upcoming Issues of *Virtual Mentor*

May: Obstetrics and Gynecology
June: Caring for a Culturally Diverse Patient Population
July: Medicine and Industry
August: Pediatrics

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FROM THE EDITOR

The Difficult Patient-Physician 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 fine.

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. Another physician may think of a patient that he or she can't cure or satisfy as difficult. In some circumstances, it may be 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

personal characteristics—demanding, deceptive, 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 make certain that a patient's annoying behaviors which might be chalked-up to "personality" are not actually a reflection of the patient's unmet 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, bigoted, and deceptive 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.

Restricting the description of a difficult relationship to patients' beliefs and behavior that prevent good care from being dispensed fails to capture the relational complexity of interactions among patient, physician, and context just discussed. As physicians, we recognize that difficult clinical encounters come with the territory and that some challenging situations are never going to be adequately addressed. At the same time, I firmly believe that the desire to help people, even those we 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.

- Understand how physicians' frustrated attempts to make patients well can lead to difficult patient-physician relationships.
- Identify problems behind "difficult" behaviors that the physician should address directly with the patient.
- Learn that all patient demands do not create obligations to provide what is demanded.
- Learn how to broaden attention to the patient's true complaint or need.

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

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CASE AND COMMENTARY

The Patient-Parent-Physician Relationship, Commentary 1

Commentary by Art Elster, MD

Case

Dr. Liu is not surprised to see Sandy Brown's name on the patient chart outside the examining room as he approaches. He hasn't seen Sandy in nearly a month. That's a record, or close to it. Sandy, now 12 years old, has visited Dr. Liu's office frequently over the past year and half. On most occasions, Sandy's mother, Martha, has a pretty good idea of what's wrong with Sandy and what Dr. Liu should do to "fix it." She calls whenever Sandy complains of not feeling well. In the past year, Sandy's symptoms have ranged from earache, cough, and flu-like aches and pains to headaches that Martha has diagnosed as "sinus" headaches. She tells Dr. Liu what antibiotics and other prescriptions Sandy should have. When she isn't sure exactly what Sandy is suffering from, Martha is terribly fearful that there is something seriously wrong with her daughter and tells Dr. Liu what tests he should run to find the problem.

Not long ago, Martha brought Sandy in saying that she had trouble breathing and had had coughing attacks every once in a while over a period of two weeks. She also mentioned that Sandy made "wheezing" noises when she tried to breathe during these coughing attacks. She told Dr. Liu that she thought Sandy might have asthma like her brother, Jack, who is 16 years old. Sandy's symptoms are very similar to Jack's. Martha asked Dr. Liu to prescribe Advair®. Jack was taking Advair® and it seemed to be working well for him, so she thought it would work just as well for Sandy. In fact, Martha said, she had seen it advertised frequently on television. It seemed to be a miracle drug for lots of people who had asthma. Dr. Liu examined Sandy and concluded that she had a mild upper respiratory viral infection. He prescribed rest and plenty of fluids and Tylenol if she should run fever. To be on the cautious side, Dr. Liu scheduled pulmonary function tests with bronchial provocation to assess for possible reversible airway obstruction. The results were negative.

The last time they were in, close to a month ago, Sandy (as reported by her mother) was complaining about having frequent stomach pains. "She rattles on about how her stomach hurts. Before it was once or twice a week, now it's very frequent...about 3-4 times a week. It must be something serious. Sandy's not a complainer, and Pepto-Bismol sure isn't working. Doctor, don't you think you should do an upper GI series to figure out what's wrong with her stomach," Martha pleaded. This time, Dr. Liu wanted to examine Sandy alone. He asked Martha to

step outside into the waiting room. Martha initially objected, but Dr. Liu simply stressed that he needed to see Sandy by herself; it was an appropriate standard of care for a child her age. Martha eventually heeded.

When he examined Sandy, asking her where it hurt, how it hurt, how long it hurt, and so on, she didn't seem overly concerned about her symptoms. She responded to his questions, simply stating that her pain moved "all around her stomach." She couldn't really describe what type of pain she was having, just that it lasted a few seconds. The pain was not associated with food or activity. Sandy had no history of upper GI symptoms such as nausea or vomiting or lower GI symptoms such as diarrhea. The physical exam was essentially unremarkable, and Dr. Liu told Martha that if Sandy's pain persisted or got more severe, she should return to see him.

Dr. Liu believes that Sandy is a rather healthy and active child, though her mother believes the opposite. She often tells him, "I love my daughter with all my heart, Dr. Liu. A mother knows when there's something wrong with her daughter. I know there's something wrong with Sandy. You must help us." No matter what he does to reassure both Martha and Sandy (though Sandy doesn't seem to need the reassurance), they appear with more symptoms. He wonders what symptoms Sandy will have and what more Martha will demand of him. Most of all, he wonders how he will manage to restrain from shouting out that Sandy's most serious problem is her mother.

Commentary 1

Sandy Brown's case is not atypical for a young adolescent with multiple somatic complaints. Dr. Liu became frustrated with his inability to make a diagnosis, reduce the symptom complex, and meet the stated needs of the mother. At this time, he should have taken a step back and reassessed the course of Sandy's medical history. If he had done this, he probably would have realized that he most likely was looking at the wrong patient.

One of the major diagnostic and management challenges of adolescent medicine is to distinguish relative organicity from psychogenicity. This mind-body connection exists with patients of all ages but is prominent during adolescence due to rapid physical and psychological changes and emerging issues surrounding emotional independence from parents. Adolescents often have somatic complaints such as headaches, fatigue, and abdominal pain. Although major organic disease certainly occurs, it is rarely associated with only single symptoms and lack progression of symptoms.

In this particular case, Dr. Liu should have become suspicious during the past year that Sandy had a psychogenic cause of her symptoms. There were several tip-offs to this: the vague and changing nature of the supposedly organic problems, the lack of progression of any obvious disease state and, importantly, Sandy's lack of concern. The mother, and Dr. Liu, wanted Sandy to have a disease that could be fixed.

As physicians rely on standard markers of pediatric development, so should they for adolescent development as well. These markers include progression of pubertal development, academic performance, friendship development, and family relationships. Dr. Liu could relatively easily obtain information that signaled problems with Sandy's physical and psychological development. For example, are her school grades dropping? Is she missing social functions due to the physical symptoms or to lack of energy? Is she arrested in the development of her secondary sexual characteristics? Is she losing weight? Are there increasing conflicts with her parents? School grades, like a reduction of platelets in early disease, are usually the first sign of either emotional or physical distress. One of the most important assessments that physicians can do is to compare a teen's last semester grade point average with what he or she is making now. Any two-letter grade drop in average should cause concern.

Another area that Dr. Liu failed to assess is the family context surrounding Sandy. Has the family relocated recently? Has there been a recent death in the family of a close relative? Has a parent lost his or her job? Are there marital problems? Do the parents or other siblings have health problems? Are there drinking problems? In this case, Dr. Liu should be highly suspicious that Sandy is the "identified patient" within a family that is in turmoil. Why is the mother so concerned? What "bad" disease does she worry that Sandy might have? Does Sandy represent a power struggle between parents within a deteriorating marriage? In addition to talking with Sandy alone, Dr. Liu should talk with the mother alone.

Lastly, Dr. Liu made one other major mistake—he failed over the past year to establish a trusting relationship with Sandy. Adolescents should be seen alone at each visit and parents should be counseled that what transpires during the exchange of information remains confidential, unless the patient is of danger to her/himself or to others. There is good evidence that adolescents are less likely to disclose sensitive information unless they are assured the confidentiality nature of the visit. In the present case, sensitive issues such as sexual abuse, domestic violence, and marital discord need to be assessed. Disclosure of this information is enhanced if Sandy knows that Dr. Liu is her's, and not her mother's doctor, if she is approached in an authoritative rather than authoritarian manner, and if she trusts that what she shares with Dr. Liu will remain confidential.

In summary, over the past year, Dr. Liu has permitted Sandy's mother to control the diagnostic and management strategies employed. He failed to recognize that although adolescents often have somatic complaints, they are not fond of taking time away from school or social groups to have a medical visit. Something else is going on that Dr. Liu needs to evaluate. It is not surprising that he felt frustrated upon seeing Sandy's name on the patient chart outside of his examining room. This emotion should alert him to the fact that he has yet to establish the underlying cause of the numerous visits and changing symptom complex.

Art Elster, MD is director of Medicine and Public Health at the American Medical Association, a pediatrician with specialty in adolescent medicine, and past president of the Society for Adolescent Medicine.

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CASE AND COMMENTARY

The Patient-Parent-Physician Relationship, Commentary 2

Commentary by Patrick Staunton, MD

Case

Dr. Liu is not surprised to see Sandy Brown's name on the patient chart outside the examining room as he approaches. He hasn't seen Sandy in nearly a month. That's a record, or close to it. Sandy, now 12 years old, has visited Dr. Liu's office frequently over the past year and half. On most occasions, Sandy's mother, Martha, has a pretty good idea of what's wrong with Sandy and what Dr. Liu should do to "fix it." She calls whenever Sandy complains of not feeling well. In the past year, Sandy's symptoms have ranged from earache, cough, and flu-like aches and pains to headaches that Martha has diagnosed as "sinus" headaches. She tells Dr. Liu what antibiotics and other prescriptions Sandy should have. When she isn't sure exactly what Sandy is suffering from, Martha is terribly fearful that there is something seriously wrong with her daughter and tells Dr. Liu what tests he should run to find the problem.

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Dr. Liu believes that Sandy is a rather healthy and active child, though her mother believes the opposite. She often tells him, "I love my daughter with all my heart, Dr. Liu. A mother knows when there's something wrong with her daughter. I know there's something wrong with Sandy. You must help us." No matter what he does to reassure both Martha and Sandy (though Sandy doesn't seem to need the reassurance), they appear with more symptoms. He wonders what symptoms Sandy will have and what more Martha will demand of him. Most of all, he wonders how he will manage to restrain from shouting out that Sandy's most serious problem is her mother.

Commentary 2

It seems that Dr. Liu thinks that Martha is the problem and not her daughter, Sandy. However, Martha is requesting help for her daughter and not for herself. The challenge for the physician is how best to help Martha without condemning her and thus rejecting her.

I believe that Martha's fears and concerns are genuine but that the object of her concerns is misplaced. Accepting the legitimacy of her fears and concerns is an essential step for the physician to obtain Martha's trust and confidence. With this in mind, Dr. Liu should talk with Martha alone and find out more about what she, Martha, thinks about Sandy and what is going on in her (Sandy's) life. How is Sandy doing at school? What kinds of social activities is she engaged in? Has she started to menstruate? What does Martha expect of Sandy? What does she most fear might happen to her daughter? The answers to these and related questions might help shift Martha's preoccupation with Sandy's body to the larger picture of her overall growth and development and where she (Martha) fits into that picture.

Martha certainly needs help but shouting at her that she is the problem will help neither her nor her daughter. When you are feeling morally judgmental or beginning to feel angry towards a patient or family member, it's a good time to step back a bit and review your assessment. On reflection, there may be another approach that makes more sense to you and is more helpful to your patient. Consultation with a trusted colleague is often most helpful in such cases.

Patrick Staunton, MD is a psychiatrist who is retired from private practice in Chicago.

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CASE AND COMMENTARY

When a Nonadherent Patient Needs Your Care

Commentary by David A. Bennahum, MD

Case

Dr. Jefferson, an OB/GYN in private practice, first took care of Ms Carr when her mother brought the 15 year-old girl in for a pregnancy evaluation. The test was positive, and Ms Carr's mother accompanied her daughter on every prenatal visit. After a successful delivery, Dr. Jefferson brought up the topic of birth control. Ms Carr, partly on the insistence of her mother, wanted to take birth control pills because she had heard that they improved one's complexion and didn't cause much weight gain. Concerned about the 15-year-old's ability to stick with a contraceptive that required daily vigilance, Dr. Jefferson suggested taking a longer acting contraceptive, but Ms Carr insisted that birth control pills were the only kind of contraceptive she wanted.

Over the next 3 years, Dr. Jefferson saw Ms Carr for routine care, including renewing her prescription for birth control pills, always accompanied by her mother. One day, she came in without her mother; and Dr. Jefferson learned that the 2 had had a falling out and Ms Carr had moved in with her boyfriend.

Ms Carr missed a scheduled appointment, and when Dr. Jefferson saw her again, she was several weeks pregnant. When asked why she had missed her appointments, Ms Carr replied that she couldn't make it at the scheduled time and didn't think that missing an appointment was such a big deal—she wanted to get pregnant. During the visit, Dr. Jefferson stressed the importance of prenatal care for the health of both Ms Carr and her baby and the need for Ms Carr to come to all her scheduled appointments.

Ms Carr made her next appointment before she left the office but she failed to keep it. She did not respond to several calls prompted by Dr. Jefferson's tickler file for women receiving prenatal care. Four months into her pregnancy, Ms Carr appeared without an appointment. When asked about the missed appointment, Ms Carr apologized. "I know I should have come, but I have a job and another child to take care of and now that I live with my boyfriend, your office is much farther away than when I lived with my mother. I can't take off work without being docked and I can't leave the 3-year-old after I get home. I knew you needed to see me." Dr. Jefferson was worried about how Ms Carr looked; she had gained too much weight. Dr. Jefferson went ahead and saw her at the unscheduled time. She did an exam and

got blood work. She sent Ms Carr away with a printed diet that called for less salt, decreased carbohydrates, and fewer calories in general.

The lab work showed that Ms Carr's blood sugar was elevated, so Dr. Jefferson had the office secretary call to schedule an urgent appointment because of concerns about gestational diabetes and its potential negative impact on the fetus.

Despite repeated attempts to contact her, Ms Carr didn't return to the doctor's office until 4 weeks later, now 5 months pregnant. She had gained more weight and had some swelling in her ankles. Dr. Jefferson informed her of the importance of closely monitoring and treating her diabetes, and that it might be better if Ms Carr found a physician closer to home or work whom she could get to more regularly. Dr. Jefferson said that Ms Carr's last trimester should be monitored carefully and that she, Dr. Jefferson, would help Ms Carr find another physician. Two weeks later, Dr. Jefferson was happy to receive a request from a colleague for Ms Carr's medical records.

One month later, Dr. Jefferson received a call from labor and delivery at a hospital where she attends. A nurse's aide said that Ms Carr had showed up at the ER in premature labor and had been admitted. When asked who her doctor was, Ms Carr promptly gave Dr. Jefferson's name.

Commentary

In this case a young girl, Ms Carr, who had her first child at 15, was compliant with her physician, Dr. Jefferson's, recommendations as long as she lived with her mother. At 18 she had a falling out with her mother, claimed her independence, got a job, and taking her child with her moved in with her boyfriend.

Dr. Jefferson learns all this when the patient returns for a visit without her mother. Her next appointment is missed, however, and when she next turns up she is found to be several weeks pregnant, a pregnancy that she insists she wants. Her physician is troubled, perhaps annoyed, by Ms Carr's nonchalant attitude and possibly even by the pregnancy which the doctor tried to prevent by offering long-acting contraceptives after the first baby was born. Claiming that her job, the needs of her first-born, and the distance she has to travel to reach the doctor's office are all impediments, Ms Carr misses a number of appointments. When she does turn up again she is found to have gestational diabetes. The doctor at first urges her to keep her appointments, follow medical advice, and then suggests that she find a physician nearer to her home. She does that, but then unexpectedly she shows up at the hospital in premature labor and claims Dr. Jefferson as her obstetrician.

What should Dr. Jefferson do? Should she accept Ms Carr as her patient or refer her back to the colleague whom Ms Carr recently saw? Does the physician have a duty to care for this patient? Apparently Ms Carr, realizing that she was in trouble, perhaps in premature labor, rushed to the hospital. After all Dr. Jefferson had been Ms Carr's physician since she was 15, had seen her through her first pregnancy and

continued to see her from time to time. Is Dr. Jefferson bound by a fiduciary duty to now care for Ms Carr? And if this premature baby does badly will she, Dr. Jefferson, be blamed and possibly sued? She would certainly be within her rights to think that she had not abandoned Ms Carr. On the contrary she arranged for Ms Carr to see a colleague. But what of the patient? She must now be scared, certainly no longer nonchalant, and immature, and now desperate to have the doctor she trusts and knows take care of her.

We can see at least 2 values Dr. Jefferson might consider here. The first is fidelity. Granted Dr. Jefferson has been the more faithful of the 2 in this patient-physician relationship. The second is the value of caring. The patient desperately wants a physician she knows and trusts not only to cure her but also to care for her. Will Dr. Jefferson see that trust as a gift, that Ms Carr is reaching out to her in her moment of need, rather than that Ms Carr has been careless and immature and is not worthy of further attention?

We can reject patients for so many reasons, and we are so easily put off when in the course of a busy day, someone does not follow our best advice. How we frame and name situations is very important. What do we really mean by non-compliant? Comply means to bend, and few of us wish to bend and bow before another. When a patient doesn't follow our advice, is it only because she was irresponsible? Do we ask ourselves if we were clear in our explanation? Did we ask the patients to articulate what we think we have just explained? Can the patient afford the treatment? Are there logistical problems such as Ms Carr had? Where to leave the baby? How to get a ride or money for gas? Will she lose her job if she takes too much time off? Do we really know our patients' lives their troubles and their joys? To what extent do our own values warp our judgment?

I would argue that Ms Carr's return is an act of fidelity on the part of the patient. Fidelity implies trust, and when a patient entrusts herself to a physician she brings a gift. If the physician can respond with gratitude and empathy to a patient's need, a bond will be established that will benefit both patient and physician.

David A. Bennahum, MD is a professor of medicine at the University of New Mexico.

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CASE AND COMMENTARY

Never Symptom-Free

Griffin Trotter, MD, PhD

Case

When Dr. Alverdo saw Richard Edmunds' name on the index card of appointments that the secretary handed him, he thought, "What can I possibly say or do that will make a difference?" Mr. Edmunds, a high school English teacher, was 46 and has a history seasonal allergies. Nevertheless, Mr. Edmunds was in the office, on average, every 6 weeks. His symptoms varied but were always difficult to verify or quantify—pain, discomfort, "just not feeling right."

Three months ago, Mr. Edmunds presented with complaints of headaches. He described the pain as generalized and worse in the afternoon than in the morning. The headache was not accompanied with nausea or visual changes. They never woke him from sleep and were not associated with any particular activity or food. Non-narcotic analgesics were ineffective. Based on the history and physical, which included a normal neurological exam, Dr. Alverdo concluded that the headaches were most likely caused by muscle tension and prescribed a course of anti-inflammatory medications, muscle relaxant, and physical therapy exercises. Mr. Edmunds made 3 visits to the therapist but said the exercises were not helping. He kept asking, "How do you know I don't have a tumor or an aneurysm about to blow, Doc?" Finally, Dr. Alverdo ordered a CT scan, which, he had to admit, he believed was a "shot in the dark." The scan was negative. After that report, Mr. Edmunds complained less about the headaches. Dr. Alverdo hadn't heard about headaches for a couple of months now.

Lately, Mr. Edmunds was having chest pains. Faithful about his annual physical exam, Mr. Edmunds had no previous history of exertional angina or shortness of breath. There was no known heart disease in Mr. Edmunds' immediate family. Dr. Alverdo had ordered an EKG and cardiac stress test, both of which Mr. Edmunds passed with flying colors. Then, thinking the persistent pain might be digestion-related, Dr. Alverdo ordered a barium swallow and upper GI series. Negative.

Looking at the name on the card, Dr. Alverdo thought, what's Edmunds going to want today? At the last visit, Mr. Edmunds reported that he could not sleep because of the crushing pain. The only remaining diagnostics for chest pain were highly invasive. Dr. Alverdo resolved that he would not be talked into ordering an angiogram or anything else that would put Mr. Edmunds at risk. There simply was no indication for it. He imagined how the conversation would go. Mr. Edmunds

would dispute everything Dr. Alverdo said. This generally went on for 25 or 30 minutes. "Doctor," Edmunds would say. "Do you want me to be one of those cases you read about in the paper where it says, "he kept telling the doctor he was sick, but no one believed him?"

Commentary

For years, the typical physician has been plagued by fear of omission. What if she omits a critical test, fails to consider a possible diagnosis or doesn't offer a helpful treatment? Not only would her patient presumably suffer, but she too would face threats—of diminished reputation, lawsuit, and worst of all, self-recrimination. To this fear, clinicians have recently added another source of dread. Subsequent to a recent Institute of Medicine report,¹ physicians and the public have grown increasingly aware of the way in which patients are harmed or killed through errors such as illegible writing, lapses in concentration, and the absence of systematic crosschecks.

But there is a kind of error that is arguably more important and ethically problematic. I will call it the "error of compulsion." Errors of compulsion occur when doctors feel compelled to order tests that they know to be unnecessary or not indicated. These errors tend to evolve from 3 typically overlapping sources: (1) excessive patient activism, (2) excessive physician activism, and (3) fear of recrimination. Such errors are not innocuous, since they frequently lead to needless suffering, needless morbidity and even death. They are ethically problematic because they violate one of medicine's fundamental moral maxims—the rule, often called the "principle of nonmaleficence"²; physicians should not harm patients.

Dr. Alverdo is on the cusp of an error of compulsion, and the source (at least ostensibly) is excessive patient activism. His patient, Mr. Edmunds, has a history of requesting (and getting) diagnostic evaluations that are, at best, "shots in the dark." Now Dr. Alverdo anticipates that he will be able to satisfy Mr. Edmunds only by ordering a dangerous test (coronary angiogram) that has little chance of detecting cardiac pathology. I will argue that if Dr. Alverdo orders the angiogram, he errs by subjecting his patient to an unjustified risk.

Before I make my case, however, I should concede that the angiogram might offer some benefit. First, it is possible, despite the inconclusive nature of Mr. Edmunds' symptoms and the negative workup, that Mr. Edmunds has occult coronary artery disease that would be detected through coronary angiography. Second, as Mr. Edmunds' earlier CT of the head seems to exhibit, a definitively negative test can have therapeutic value.

But a remote possibility of pathology does not justify undertaking a risk-laden procedure such as a coronary angiogram. It is rarely possible in medicine to rule out disease with absolute certainty. Physicians must make their recommendations based on probabilities, and here the probability of a coronary etiology is small. Likewise, the prospect of symptom relief through reassurance is not enough to justify the risks

of a coronary angiogram. There are other, safer ways to address Mr. Edmunds' symptoms.

If he orders another unnecessary test, Dr. Alverdo will reinforce a dangerous and maladaptive trend in his clinical relationship with Mr. Edmunds. It would be better for Dr. Alverdo to address Mr. Edmunds' compulsion for reassurance—thus averting a potentially vicious cycle of debilitating worry, followed by excessive workup, followed by new worries. Dr. Alverdo should explain the dangerous implications of this cycle. Though financial considerations also pertain (since it would be exorbitantly expensive to pursue comprehensive testing for every unlikely diagnosis), Dr. Alverdo should focus on what is best for Mr. Edmunds. Somehow, Mr. Edmunds must come to terms with medical uncertainty. To wit, he must understand that it is not possible to explain every symptom and it is dangerous to try.

In his references to newspaper cases where the patient "kept telling the doctor he was sick, but no one believed him," Mr. Edmunds opines that undiagnosed pathology is the "worst case" scenario for patients with chest pain and other symptoms that could be linked to dangerous conditions. The response, for Dr. Alverdo, is to explain that exceptional cases do not make good precedents. The real "worst case" scenario occurs when patients die in the course of unnecessary testing. Would Mr. Edmunds choose a very low probability of finding occult pathology when it brings a higher probability of suffering unnecessary complications? Occasionally, such frank discussions fail to help patients overcome their medical worries, and psychiatric referral is indicated.

Excessive patient activism is a corruption, through excess, of the principle of autonomy—ie, the principle that competent patients ought to have the prerogative to decide for themselves. Though patient autonomy is important, it does not compel physicians to offer dangerous or unhelpful interventions. Often excessive patient activism is indirectly encouraged by physicians. In such cases, the real culprit may be excessive physician activism—an overly developed instance of physicians' commendable inclination to "do something" for suffering patients. When it is not tempered by prudence and caution, this powerful motive begets a dangerous "technological imperative." Despite their activist tendencies, and despite fears of legal liability, physicians are beholden primarily to cultivate and protect the well-being of patients. This objective is not served when physicians cave in to imprudent demands.

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CASE AND COMMENTARY

When Disability Is in Question

Guy Micco, MD

Case

Dr. Lowe, a family practice physician, has been following Mrs. Darrell for many years—since her kids, now grown and married (one divorced) were in their teens. She is 56 years old, has diabetes, for which she takes glyburide, and is overweight, but active. She raised the 4 children on her own and is now serving in the role of "mother" to one of her granddaughters.

Mrs. Darrell works from 10 to 4 each day as a certified nurse's aide. She was employed by an agency that supplied home care personnel for the chronically ill, those convalescing, and, increasingly, for elderly individuals who wanted to stay in their own homes. Through the agency, Mrs. Darrell was assigned to a particular client, a woman in her 80s who wanted daily help. Mrs. Darrell cemented a relationship with the client and, after a few months, left the agency and made a private arrangement with her client.

Mrs. Darrell was involved in a traffic accident about 3 months ago. Standing at a rural railroad crossing, about third in line, Mrs. Darrell was hit from behind. The car was not traveling fast, and Mrs. Darrell did not hit the car in front of her. She came to Dr. Lowe the next day with neck pain. Her neurological exam was nonfocal and consistent with muscle strain. He prescribed some non-steroidals and told her to wear a cervical collar. He told her to come back if her neck did not feel better in 7 to 10 days. When Mrs. Darrell returned in 3 days, the pain was worse, not better. Her shoulder hurt now, also, and she said that she felt weaker in her left arm; she had trouble supporting her client, who weighed 128 lbs, when helping her in and out of her wheel chair or while bathing her.

On exam, it was difficult to assess whether there was asymmetric strength in her upper extremities, but given the trauma history, Dr. Lowe ordered an urgent cervical MRI. The results of the MRI were negative for nerve compression or bony abnormalities. In addition to the non-steroidals, Dr. Lowe prescribed a muscle relaxant and physical therapy.

A week later, Mrs. Darrell returned with complaints that the pain was not getting better. She was unable to work and asked whether Dr. Lowe could help her get disability status form the Social Security Commission. Dr. Lowe asked whether she might not get some workman's compensation for a while to see whether the neck

and shoulder pain resolved. This is when Mrs. Darrell told him that she had left the agency and was working directly for 1 client. Dr. Lowe had assisted in the disability process before and knew it was important to be precise and get the facts straight. In further questioning Mrs. Darrell about her work, he discovered that Mrs. Darrell had an "off-the-books" arrangement with her client. The elderly woman was not withholding income tax from Mrs. Darrell, was not paying employer's social security benefits, and was paying Mrs. Darrell in cash each week. In other words, Dr. Lowe conjectured, Mrs. Darrell could easily continue this arrangement while receiving disability payments, and no one would be the wiser.

Dr. Lowe likes Mrs. Darrell—she's a survivor. She raised those kids on her own without complaint or bitterness and enjoys having a young one to take care of now. He imagines that she's a welcome companion and more-than-competent caregiver to her client, but he seriously doubts that she has an injury that warrants permanent disability status.

Commentary

We are presented with the story of a hard-working, middle-aged woman (Mrs. Darrell) who, now 3 months after a whiplash injury, is asking her physician (Dr. Lowe) for help in obtaining disability status from social security. The question that arises concerns the problem of how a physician might best respond to such a request when he "seriously doubts that she has an injury that warrants permanent disability status."

One problem to consider right off concerns how much Dr. Lowe knows about disability under state and federal law. It is his place to provide medical evidence regarding disability to both state and federal agencies. Mrs. Darrell need not qualify for "permanent disability status" in order to receive some benefits. Briefly, I encourage all physicians to learn about state and federal laws on this matter. There are 2 forms of federal social security benefits: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). SSDI is funded through social security taxes withheld under the Federal Insurance Contributions Act (FICA); and, if awarded, the benefit amount is based on prior income. If Mrs. Darrell has not had FICA taxes withheld from her paychecks (with equal contributions made by her employer) for at least 5 of the past 10 years, she will not be eligible for this benefit, regardless of her disability status. SSI is funded by "General Revenue" (general tax revenues), and it is not based on prior work. In addition to being "disabled," in order to qualify for SSI, Mrs. Darrell would have to have very limited resources.

Both SSDI and SSI are administered under the Social Security Administration. The definition of disability in the Social Security law is a strict one. The following definition is from the Social Security Administration website¹:

"To be eligible for benefits, a person must be unable to do any kind of substantial gainful work because of a physical or mental impairment (or a combination of impairments), which is expected either:

(1) to last at least 12 months, or (2) to end in death.

If, because of a medical condition, a person cannot do the work that they performed in the past, then age, education, and past work experience must be considered in determining whether the person can do other work. If the evidence shows that the person can do other work, even if it involves different skills or pays less than their previous work, they cannot be considered disabled for Social Security purposes."

Mrs. Darrell will probably not qualify for either SSDI or SSI—but, she may. If not already started, now is the time for Dr. Lowe to begin to document the severity of his patient's disability. Though unlikely, should it become impossible for her to return to work, this information will be invaluable in helping make her case for benefits.

In California and some other states (including New York, New Jersey and Hawaii) there is a State Disability Insurance (SDI) program. Most California employees are covered by SDI, which is funded through payroll deductions and "provides affordable, short-term benefits to eligible workers who suffer a loss of wages when they are unable to work due to a *non work-related* illness or injury"² Under SDI, "disability" is more liberally defined² and needn't be expected to last for any particular period of time. In addition, it has a waiting period of only 1 week and may last up to 52 weeks. Here's the good news for Mrs. Darrell (and her current employer): her earnings approximately 5 to 17 months before any disability claim were to be submitted would determine her benefits. Since she may have been working for an agency during this time, she may well qualify.³

One last source of financial relief for Mrs. Darrell would be from the auto insurance that she and/or the person who hit her might have. There is a statutory minimum limit of liability insurance that all drivers must carry in California. For bodily injury, this (lower) limit for any 1 accident, is \$15,000 for death or injury of any 1 person. Some, perhaps most, of this insurance money would go to cover Mrs. Darrell's medical expenses (including her health insurance company's recovery of the cost of Dr. Lowe's office visits, X-rays, MRI, and any physical or other therapy), but some dollars would probably be left over to compensate her for lost wages and, perhaps, pain and suffering. If the person who hit her from behind had no such insurance, then perhaps she has "uninsured motorist" insurance that would be helpful in this regard.

Finally, regarding the problem that we are most clearly presented with in this case: Dr. Lowe's distrust (his "serious doubts") regarding Mrs. Darrell's disability claim. These 2 people have been in a doctor-patient relationship for many years, a relationship that seems to have been good. Good relationships, of course, require trust, or at the least, when trust is in doubt, a willingness to talk openly about problems. Dr. Lowe should speak honestly about his concern that his patient's injury does not warrant permanent disability status. She may well agree! Mrs. Lowe may understandably be very anxious about how long her pain and inability to work will continue. Hearing that these will likely pass in the forthcoming weeks may be good news to her. I believe physicians should take the position that, absent of clear and convincing evidence, their patients are telling the truth. Here there is no such

evidence to suggest Mrs. Darrell is lying. Indeed there is no evidence possible to convince one that someone else is or is not in significant pain other than the testimony of the person in pain. Dr. Lowe should believe his patient, and begin an ongoing conversation about her ability to return to work. Together they should develop a plan for physical therapy and other modalities that will help her with pain relief and the return of her functional status—for her sake, not the sake of whatever insurance, state or private, that might afford her financial benefit This is what is required of a good doctor-patient relationship.

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3. Her wages in question must have been subject to the SDI tax, which they most certainly were (in California and certain other states). Her wages from her current employer – though not paid – were also subject to those taxes. As well, her current employer was, contra federal law, not paying "Nanny taxes" which would fund SSDI.

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IN THE LITERATURE

Physicians' Responsibilities in the Face of Patients' Irrational Decisions

Faith Lagay, PhD

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 a 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 requests for or refusals of treatment appear 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, eg, 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 belief 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. Physicians should respect the value that patients place on avoiding pain and suffering while attempt to help 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 belief or cultural value (eg, 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

When faced with irrational decisions, physicians must be certain that the patient understands the treatment and non-treatment alternatives and their consequences. Physicians should also be aware that they can 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. Presenting the options in different ways can minimize framing effects.

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. Physicians have a responsibility to try to change the irrational decisions of competent patients, but irrational choice does not, in itself, constitute grounds for declaring that a patient's decision making capability is compromised. A judgment of compromised decision making capability is the only justification for overriding a patient's irrational treatment or non-treatment decision. In the presence of decision making capacity, irrational decisions must be respected if the patient cannot be persuaded non-coercively to change them.

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IN THE LITERATURE

Who Is Being Difficult? Addressing the Determinants of Difficult Patient-Physician Relationships

Michelle Lim

Both the patient and physician bring to the medical encounter social and personal characteristics that contribute to defining the nature of the patient-physician relationship. When patient or physician or both feel frustrated with the medical encounter, the situation may lead to poorer health outcomes. In a 1989 article in the *Journal of Family Practice*, Thomas L. Schwenk, MD, et al cite several studies that address the difficult patient-physician relationship by looking at characteristics of patients who have been labeled difficult by physicians.¹⁻⁵ These so-called difficult patients are seen as demanding, non-compliant, manipulative, and self-destructive.⁶ But focusing on just the patient member of the dyad gives the illusion that the patient is the wrongdoer in the relationship. A physician who wishes to ease the troubled relationship, may turn to a catalog of psychological conditions as explanations for the patients' behaviors. This solution is limited and does not consider the influence of the physicians' roles in the relationships.

Schwenk et al also illustrate how differing physician and patient expectations can produce mutually negative outcomes in the medical encounter.⁷ In "Physician and Patient Determinants of Difficult Physician-Patient Relationships," the authors explain that among the family physicians they surveyed the primary motivations for practicing medicine were the desire to help people and the attraction to the problem-solving challenges specific to medicine. When these goals are not met in dealing with a particular patient, the physician is apt to think of that patient as "difficult."

They found that the complexity and ambiguity of the medical problem (medical uncertainty) and the perceived abrasive behavioral style of the patient (interpersonal difficulty) also contribute to the description of "difficult patients."⁸ They conclude that when a patient's medical problems or personality make it difficult for the physician to experience professional satisfaction, the physician views the patient as difficult. Physician and patient dissatisfaction coupled with the unmet expectations produce the difficult patient-physician relationship.⁹

Other studies extend the story to the patient's point of view.^{6, 10-12} These studies suggest that patients' unmet expectations and their dissatisfaction with physicians' clinical behaviors are primary causes of their frustrations with the patient-physician relationship. Greiner points out 2 traditional physician views that present barriers to

an ideal patient-physician relationship: the concept of the difficult patient and a biomedical view of medicine that tends to exclude social conditions. He suggests that physicians have definitive opinions about what is "medically appropriate," leaving little room for patient questioning and negotiation. This inflexibility in the medical encounter leaves already vulnerable patients in an even more handicapped position. Patient attempts to negotiate often result in expressed animosity on the part of health care providers.¹³ A setting like this leaves patients thinking they cannot be active participants in their health care.

A study by Robert Bell et al found that patients with at least 1 unmet expectation reported less satisfaction with their medical visits, less improvement in their health status, and weaker intentions to adhere to physician recommendations. By the same token, physicians saw these patient visits as frustrating and more effortful.¹⁰ These encounters may be filled with misunderstanding from both sides. Judith Hall, PhD et al surveyed diabetic patients and their primary care physicians in an effort to assess physicians' awareness of their patients' emotions, satisfaction, and opinion about the quality of their communication.¹¹ They found that physicians tended to see patients' responses as more negative than they actually were. The authors requested that patients rate their opinions regarding quality of communication, satisfaction, and experience of 6 emotions (anger, worry, disappointment, pleasure, cheerfulness, relief). The physicians were asked to estimate the patients' views for each of the questions.¹⁴ Hall et al conclude that physicians had limited accuracy in estimating their patients' opinions and feelings. Moreover, in focusing on the negative signals, physicians may be guilty of failing to properly read affective responses from their patients.¹⁵

Taken together, these studies suggest that a difficult patient-physician relationship emerges from the conflicting expectations and misunderstood behaviors by both patient and physician. They also suggest that focusing on the concept of the difficult patient and the catalog of psychological characteristics of so-called difficult patients is not an effective solution for dealing with an unsatisfactory patient-physician relationship. Rather than categorizing patients as "difficult," the authors of these studies emphasize the value of partnership and teamwork in remedying a broken patient-physician relationship. They also call on physicians to respond with more empathy to their patients' needs and keep open minds when dealing with patient requests.

Herbert Adler believes that a collaborative relationship is also a therapeutic alliance that produces mutual benefits for the patient and physician. He proposes that, in crafting the patient-physician relationship, both patient and physician are collaborative partners "engaged in a common struggle against [the patient's] malady."¹² "The secret of care of the patient is caring for the patient,"¹⁶ Adler cites, adding that "caring" is "responsive listening."¹⁷ A successful patient-physician relationship is one of flexibility, continuity, and mutual respect. By looking beyond the medical conditions of the patient, physicians can work side-by-side with their

patients to devise more successful strategies for clinical negotiation and thus effective treatment.

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HEALTH LAW

Can Patients Contribute to Medical Negligence?

Lisa Panique

The day before Mrs. Clark was scheduled to undergo a breast biopsy she filled out a hospital form entitled, "Admission Information and Nursing Care Data." A nurse assisted Mrs. Clark in completing this form, and under the heading "medications," Mrs. Clark disclosed to the nurse that she had been taking the drug Lasix before her admission to the hospital. The purpose of this form was to help the hospital and nursing staff provide proper care to Mrs. Clark before and after the surgery and to make sure that she received any medications that she had been taking at home. The form was not included in Mrs. Clark's chart, nor did any of her physicians see the form prior to her procedure.

On the day of her biopsy, Mrs. Clark met with 2 physicians. Each physician asked whether she was taking any medication and Mrs. Clark answered "no." One of the physicians asked Mrs. Clark whether she suffered from heart disease, to which she answered "no." Trusting this information, the 2 doctors proceeded with the biopsy. During the procedure, Mrs. Clark suffered cardiac arrest, which ultimately caused irreversible brain damage.

Legal Analysis

The above facts are adapted from *Mackey v Greenview Hospital*.¹ Mrs. Clark's family sued the doctors for medical malpractice. Rather than just taking the defensive position, the doctors responded to the allegations with charges of their own. This "affirmative defense," as it is called, answered the plaintiff's claim by charging Mrs. Clark with "contributory negligence." The doctors argued that Mrs. Clark's failure to disclose her full medical history was the proximate cause of her cardiac arrest and resulting brain damage. The jury agreed with the physicians and dismissed the case, and the plaintiffs appealed.

The central issue before the appellate court was to determine how significantly Mrs. Clark's failure to disclose affected the quality of care given by the hospital and defendant physicians.² When the court analyzes the quality of care and diagnosis issue such as the one in this case, it can only examine the circumstances that were available to the physicians at the time. Thus, the court asked whether, given the circumstances and information available to them, Mrs. Clark's physicians should have been aware of her condition. The court recognizes, in addition, that patients are responsible for exercising ordinary care in revealing information to their physicians and that physicians have the primary responsibility for eliciting an

accurate history from their patients due to their greater wealth of medical knowledge. This responsibility cannot be fully achieved without the truthful admissions of the patient. Thus, if the patient willfully chooses to withhold information from the physician, the physician cannot be liable for a negligent misdiagnosis.

The appellate court was left to consider whether the defendant hospital and physicians had presented evidence of contributory negligence sufficient to persuade the trial jury to believe that Mrs. Clark's failure to disclose contributed to the substandard care. The defendants did not need to present conclusive proof of Mrs. Clark's contributory negligence; they needed to demonstrate only that the evidence presented at trial was sufficient to persuade the jury of Mrs. Clark's contributory negligence. The defendants had the burden of providing evidence that Mrs. Clark knew of her heart condition and failed to disclose it prior to the biopsy.

The defendant doctors presented the following evidence. About 2 weeks prior to the surgery, Mrs. Clark experienced an episode of severe chest pain and vomiting. During this episode, she was described as being sweaty and pale. The doctors also produced evidence that Mrs. Clark had been taking nitroglycerine, a drug prescribed primarily for chest pain associated with heart disease. Finally, Mrs. Clark had admitted taking Lasix, a potent diuretic also used in the treatment of heart disease.³ On the other hand, attorneys for Mrs. Clark argued that her disclosure to the nurse on the day prior to surgery should have been discovered by the defendant physicians.³ Since the physicians have the primary responsibility to develop an accurate medical history, the plaintiff's attorneys said, they should have examined the nurse's report for any further information.

Based on the above circumstantial evidence, the court upheld the jury verdict in favor of the doctors. The court reasoned that, from the evidence presented, a jury could find that Mrs. Clark suffered from a heart condition and failed to disclose this condition, which proximately caused her cardiac arrest.³ If Mrs. Clark had revealed this information to the defendant physicians, they could have postponed her procedure until her potassium levels were ideal for surgery. Since the physicians operated without the knowledge of heart disease, they can not be found negligent. Finally, the physicians did not have a binding duty to examine the nurse's report. Had they viewed the report and ignored the mention of Lasix, Mrs. Clark's failure to disclose would not have allowed the physicians to plead contributory negligence.

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STATE OF THE ART AND SCIENCE

Wilson's Disease: Diagnosis and Treatment

Audiey Kao, MD, PhD

Wilson's disease is an autosomal recessive disorder that results in copper accumulation and toxicity and occurs in about 1 out of every 40,000 people.¹ As a result of copper deposition in various organs, patients, typically between the ages of 10 and 40 years old, can present with liver, neurological, or psychiatric symptoms. In fact, one fourth to one third of patients initially present with psychiatric and behavioral symptoms.^{2,3} Kinnier Wilson, in his initial case reports, described the behavioral aspects of the disease, which he called "psychical," and noted their presence in 8 of his 12 patients.⁴

Diagnosis and Physical Findings

The Kayser-Fleischer ring, a brownish-green discoloration from accumulation of copper granules deposited in the sclera at the periphery of the cornea, is virtually pathognomonic of Wilson's disease. Wilson's disease often presents in the following ways:

- Psychiatric – the previously psychiatrically "normal" young person can present depression, manic behavior, paranoia, and delusions, but the commonest disturbances are "bizarre behavioral patterns that defy classification."
- Neurologic – the patient may present with slurred or slowed speech, tremors, dystonia, and dysphagia. Motor strength is not affected, nor are there sensory defects.
- Hepatic – the patient may present with hepatitis, chronic cirrhosis, or liver failure.

Positive screening test results include urine copper (over 100 micrograms/24 hour) and serum ceruloplasmin (below 5 milligrams/dl). For any patient in whom the diagnosis is not definitive, the gold standard is liver biopsy (over 2000 micrograms/g dry weight of tissue).

Initial Management and Maintenance Therapy

Wilson's Disease is an unusual genetic disease in that it is quite effectively treated (Table 1). Therefore, even though the disorder is rare, it is important to consider it in differential diagnosis, because failure to treat can lead to permanent damage including psychiatric and behavioral problems. The staple of maintenance treatment is zinc, which has much fewer side effects than previous medications such as

pencillamine. Zinc's use as treatment for Wilson's Disease was discovered when it caused copper deficiency while being studied as an antisickling agent in patients with sickle cell anemia.⁶ Zinc acts by inducing intestinal metallothionein, and thus, prevents absorption of copper into the circulation.

Table 1: Anticopper Therapy for Different Categories of Wilson's Disease Patients	
Category of patient	Treatment of choice
Initial presentation Psychiatric Neurological Hepatic	Tetrathiomolybdate Tetrathiomolybdate Tientine and zinc
Maintenance therapy Maintenance and initial therapy Presymptomatic Pregnant Pediatric	Zinc Zinc Zinc Zinc

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POLICY FORUM

A Responsible Patient

Swathi Arekapudi

The expectations of physicians--such as physicians' responsibility to make their patients' health their top professional priority--are articulated well and frequently in the literature. Much is spoken and written about patients' rights to certain health care services such as receipt of emergency care whether or not they can pay for it.¹ It is far less common, however, to read about patients' responsibilities in the medical setting. As the health care profession and patients themselves increasingly value patient autonomy, it becomes more urgent that patients take responsibility for their role in their own health care. The lack of literature on the subject suggests a lack of emphasis on the patients' roles in maintaining and improving their own health. With increasing patient autonomy, patients expect to be well-informed partners in the health care dialogue and are given greater freedom to decide if, how, and when they are going to accept medical care. Yet with the increased emphasis on autonomy, there is a congruent need to highlight patients' responsibilities for their own health; these responsibilities seem to get lost in the shuffle for patient rights and physician responsibilities. A patient-physician relationship that is built on good communication with both parties knowing what the other expects will best serve the patient's health.

The move from overt paternalism towards increased patient autonomy is illustrated by the change in the adjectives used by medical authorities over the course of a century to describe patients who do not follow medical advice. The terms evolved from the "vicious" and "ignorant" TB patients of the early 1900s, the "recalcitrant" after World War II, to the "non-compliant" patient that emerged in the 1970s.² Ironically the term non-compliant, which was developed specifically to be a non-judgmental phrase, has been criticized for its implication that patients should necessarily follow physician recommendations. "Non-adherent" is suggested as a better term because it lacks the implication that patients must necessarily follow their physicians' advice.² No doubt this new term will face a slew of criticisms in time.

Oftentimes terms like "non-compliant" are applied to marginalized people such as alcoholics, minorities, or immigrants. Indeed, trying to "predict" who will be non-compliant leads some physicians to withhold treatment, such as triple-drug therapy for HIV infections, from IV drug users who the physician thinks would not adhere to the treatment. Non-adherence to HIV drug regimen presents a danger not only to the patient as an individual but to the whole community, inasmuch as this behavior

may lead to the development of drug-resistant HIV strains. Hence some physicians withhold treatment from patients they feel will not comply effectively.³ Even though a doctor cannot oblige a patient to adhere to medically indicated treatment, he or she still has a responsibility to make sure that the patient adheres. Yet denying patients treatment based on predictions of future behavior does not seem like the best way to ensure patient health. The introduction of patients' responsibilities into this equation will help to solve this seemingly intractable problem.

Some of the problems that arise when a physician encounters a "difficult" patient, such as one who does not adhere to treatment, might be mediated by good communication and a physician's explanation of the patient's responsibility for his or her own health. Patients' responsibilities, as listed in the American Medical Association's *Code of Medical Ethics*, Opinion 10.02, include, but are not limited to the responsibility to:

1. Be truthful and express their concerns clearly to their physicians.
2. Provide as complete medical history as possible.
3. Request information or clarification when they do not fully understand their health status or treatment.
4. Cooperate with agreed-upon treatment plans and appointments.
5. Take personal responsibility when they are able to prevent the development of disease.
6. Consider participating in medical education by accepting care from medical students, residents, and others.

The above list provides a general picture of what is expected of patients. The complete Opinion can be found online. These responsibilities are not burdensome in their expectations and they generally serve the patient directly or the health of the community in general.

The modern patient-physician relationship is grounded in the autonomy of the patient and the need for the patient to make informed decisions. As we move away from the paternalism that formerly characterized patient-physician relationship, we see that active communication between the physician and the patient is invaluable in the patient's informed decision making. The goal of a physician, namely to improve or maintain the health of his or her patients when possible, can be accomplished by increasing the number of patients who adhere to recommended therapy. Though collaboration and cooperation are necessary they do not necessarily put the physician and the patient on equal footing in terms of medical knowledge. But through a patient-physician relationship built on a mutual understanding of what is expected of the other, patients will be able to understand their role in their own health care. Though physicians can no longer "order" patients to follow medical instructions they must now educate patients about the medical consequences of accepting or refusing treatment. The best method for achieving the goal of patient health is open communication between physician and patient.³

Labeling a patient "difficult" or "non-compliant" will weaken the bond of communication between doctor and patient.

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PERSONAL NARRATIVE

Midnight Encounters

Gary Fontan, MD

"You'll die sooner or later if you continue to stick dirty needles into your arms."

"You're right doc. I promised myself to get signed into the rehab program this week."

"Have you ever tried the program?" I asked.

"Yeah, lots."

"Why is this time any different?"

"Because you told me that I was going to die."

"OK, OK, let me see your arm."

It was too late at night to be having such an in-depth conversation with a drug user. I began to take the dressing off his forearm and all I could think about was that someone should take pictures of this guy and show it to high school students. This is what drugs do to you. Not your brain frying in a pan but physically disforming your body. Holding you captive, only to let you out at 2:30 in the morning so that you can come into the ER and wake me up. Just then the smell of his dying arm woke me from my dream. I had to step back so I wouldn't vomit.

"Haven't you been taking care of this?"

"I change the bandages every couple of days. Even more pus is coming out," pointing to the hole in his arm.

"Are you still taking antibiotics?"

"Yeah, I guess so."

"What's the name of them?"

"I don't know. Some yellow pills the doc gave me."

"Did you finish taking all of them? Never mind, I'll get you some more."

I couldn't get over how swollen both of his arms were. Every inch of skin, every vein and artery, was covered by scabs and scars. It looked like Grand Central Station. I began to laugh to myself, thinking anything can be funny when you're this tired.

"Do you shoot up your legs too?"

He nodded and lifted up his torn jeans. The legs were just as good as his arms. I had the urge to vomit once more. I took out a scalpel and started to cut away some of the dead tissue on his arm. This guy didn't even flinch.

"When's the last time you used?" I asked.

"Tonight."

Well if he didn't mind the pain neither would I. Then the thought crossed my mind.

This guy needs to be in the hospital for IV antibiotics but I know he'll sign out

AMA as soon as he gets the urge to use. I asked anyway,

"Do you want to stay in the hospital?"

"Na doc, got things to do. Just wrap it up and I'll be on my way."

Under his breath I heard him muffle something about doctors just wanting to get more money. I finished the dressing and told him thanks. Thank you for making the decision.

"See ya later doc."

He picked up his prescription and left. I went back to sleep.

During my psychiatry rotation in medical school we were required to take a couple of night calls at the university medical center. In the middle of one, the resident and I were called down to evaluate a patient in the emergency room.

"SOB, why are we being called to evaluate the patient?" I asked.

"I don't know, maybe he feels short of breath when he's dreaming," answered the resident.

We both tried to laugh but it was too late in the evening or too early in the morning, about 4 o'clock. Either way I was becoming annoyed with seeing this patient. Aren't there any Internal Medicine docs that can see this guy, I thought to myself. Feeling impatient, I knew all my questions would be answered as soon as we got there. We walked into the room to see a middle-aged male dressed in a dark suit and tie, sitting on top of the stretcher, hunched over, clearly out of breath, with an oxygen line to his nose.

"We need to know what this guy's O₂ saturation is."

"Yeah," the resident responded.

Just then the nurse walked in and said, "98 percent. 98 percent—normal."

The resident then asked, "Why does he have the nasal cannula on?"

"Oh, he came in with that," she said with a chuckle as she left.

Becoming more and more impatient and angered, I went up to the patient to examine him. Obviously no one else had a serious interest in him. After looking around the room I noticed that the oxygen tubing was not connected to the wall.

"I can breath easier when I wear it," the patient announced.

Systematically, I followed the tube from his nose, down around his neck, across his back, and straight into his back pocket. I pulled the tube out and showed it to the resident.

"I guess that's why they called us," he answered.

The nurse popped back in and said, "He always acts like he's out of breath when a new doctor comes in."

We spent over an hour discussing why the patient came in, his past medical history, social history, medicines, and everything in between. We learned that the day program he participated in did not open until 6 am. In the end I think he just needed a place to stay for awhile. The sun was just beginning to peek through the windows when without saying a word he got up, put on his hat, coat, and left. I went back to sleep.

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