

Virtual Mentor
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FROM THE EDITOR

Patient-Physician Relationships: Gone or Evolving?

Encounters between individuals are as an essential part of medicine as they are of life. The cases in this issue of *Virtual Mentor* describe challenging encounters in clinical medicine, and their commentaries share an emphasis on the importance of communication between a patient and physician. The articles that fill out the issue explain the importance of the patient-physician relationship and the factors that are shaping it, examine connections between poor communication and risk of litigation, recount an unlikely situation in which a relationship between a “frequent flyer” and physician developed, and introduce a program designed to help medical students build relationships with patients. Patient-physician relationships, as well as encounters between professionals, are often difficult, complicated by both internal and external factors. Yet there are ways that we, as physicians, residents, and medical students, can improve our ability to develop and nurture these relationships.

In the first case, a web-savvy patient researches his symptoms and treatment options on the Internet and relays what he thinks his treatment should be to the physician. David Anthony describes how the rise of accessible medical web resources has slightly changed the patient-physician balance of information in a way some physicians view as a challenge to their authority and expertise. But, he suggests, physicians can use the knowledge of their patients to improve patient care and develop patient-centered relationships that further enhance shared decision making. He also challenges physicians to become familiar with trustworthy web resources so they can guide their patients to reliable online sources.

The physician in case two is contemplating whether or not to offer participation in a phase I trial to the parents of a teenager who has aggressive terminal cancer. Thomas W. LeBlanc and Philip M. Rosoff explain how the mere offer of trial participation can create a therapeutic misconception in the patient and his parents—to the extent that they believe the trial has a real chance of providing therapeutic benefit, when in reality the chance of benefit is virtually nonexistent. The commentators examine the physician’s duty to act in the patient’s best interest versus his or her duty to inform patients of all options and the broader topic of the importance of phase I oncology trials for the advancement of medicine. In their commentary, Courtenay R. Bruce and Anne Lederman Flamm focus on the duty of physicians to inform patients and allow for autonomous decisions. While they acknowledge the reality of the therapeutic misconception, they argue that full disclosure in the informed-consent process provides patients (and parents, in this case) with the information they need to make a decision, thereby respecting their autonomy. They also discuss the concept of assent in situations in which the patient is not legally competent to give consent.

The third case presents a mother who takes her 4-year-old daughter to several pediatricians, and ultimately settles on one who is willing to prescribe antibiotics for her daughter. The case also includes a disagreement between two physicians in the same office over the child's treatment. D. Micah Hester views the case as a series of missed opportunities for good communication, not only between the physician and the parent, but also between the two physicians who treat the child. Benjamin Levi speaks to miscommunication in the scenario, but also comments on problematic aspects of the second physician's clinical judgment in prescribing treatment that was not medically indicated.

In the clinical pearl, Natalie A. Brooks outlines management strategies for type 2 diabetes, the chronic condition that is the basis for the first clinical case. She emphasizes that treatment decisions must be tailored to individual patients.

One question that is central to this issue is whether or not a good patient-physician relationship even matters. In the journal discussion, Scott B. Grant addresses the questions not only of whether or not the patient-physician relationship is important, but what factors improve or stress it. He explains and critiques two models that the journal article authors propose as blueprints for a good relationship.

Kelly Dineen tells a compelling story in the policy forum of the importance of professional caregivers' adherence to their scope of practice. In the new model of comprehensive patient care, physicians alone cannot meet the full range of the patients' medical and health-promotion needs, and because of this, physician assistants and advanced practice registered nurses are included in health care delivery. She identifies physicians' responsibilities for overseeing and collaborating with them.

In the medicine and society article, Howard A. Brody describes two forces that are shaping the patient-physician relationship: the medical home and pay-for-performance. He argues that, while the idea of the medical home threatens the one-on-one nature of the traditional patient-physician relationship, it broadens and enhances the relationship in ways that are, on balance, more significant. On the other hand, he believes that pay-for-performance will not improve relationships between patients and physicians and recommends approaching this concept with wariness. As technology progresses, physicians have the ability to treat patients more competently. These advances do not necessarily have to replace the relationships between patients and physicians that are the core of medical practice.

At a time when many physicians are lamenting changes in medicine that have significantly diminished their ability to develop relationships with patients (e.g., increased amounts of paperwork, shorter office visits), Chris Brooks relates the story of patient-physician relationships in an unlikely setting—the emergency room. He describes a “frequent flyer” patient who visited the emergency room on an almost

daily basis and developed relationships with staff members that allowed them to care for him more compassionately and in a resource-conscious way.

As medicine has become more technical, medical education has increasingly focused on the knowledge of disease processes, often squeezing out time for considering the important relationships between patients and physicians. In light of this, some medical schools have attempted to renew the emphasis on relationships in medicine. Arno K. Kumagai discusses the 2-year Family Centered Experience at the University of Michigan, which pairs medical students with community members who have chronic or serious diseases. He describes the goals, benefits, and challenges of this program.

Kristin E. Schleiter, in the health law piece, explores the subject of medical malpractice litigation. According to documented studies, patients who have good relationships with their physicians are less likely to file complaints in the event of an adverse medical outcome.

Relationships in medicine are as important now as they were in the past. Today's technology allows physicians to do much more to treat diseases, but this enhanced ability need not replace physicians' communication and ability to empathize with patients. In other words, the ability to treat the disease must not undermine the ability to treat the patient with the disease. As the articles in this issue demonstrate, relationships are still, and will continue to be, an essential element of medicine. With so many factors competing for the physician's time and energy, we must not lose sight of the importance of communication, empathy, and knowledge of the patient as a person.

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CLINICAL CASE

Low-Tech Solution to a High-Tech Problem

Commentary by David Anthony, MD, MSc

Mr. Jones visited Dr. Green because he had developed an infection on the bottom of his right foot. Before his appointment, Mr. Jones looked up his symptoms on the Internet and found that they could be indicative of type 2 diabetes. After examining Mr. Jones, Dr. Green ordered a fasting glucose test.

The test results showed a glucose level of 250 mg/dL, which indicated that Mr. Jones did indeed have type 2 diabetes. Dr. Green informed Mr. Jones of the results by telephone and asked him to come in to discuss treatment options and lifestyle changes that would help him get control of his diabetes.

“I have read about diet and exercise options for diabetic patients on the Internet, but I don’t think that I can make that sort of change,” Mr. Jones said. “I would prefer to start on medication right away.”

During the next visit, Dr. Green agreed that if Mr. Jones was not willing to make lifestyle changes he should start medication. He wrote a prescription for metformin, a first-line treatment for type 2 diabetes. When Mr. Jones looked at it, he said to Dr. Green, “I have also researched treatments for type 2 diabetes and would prefer to have the newest and best treatment. I can’t remember the name but it is a combination of two drugs.” While Dr. Green knew that this treatment was often an effective option, he was also concerned about using a more potent and expensive treatment before he had seen the effects that metformin had on Mr. Jones’s glucose levels.

Commentary

This scenario is becoming increasingly common as more patients access web-based health information prior to and after visiting a physician. The case displays the potential advantages and pitfalls of this new dynamic in medicine. Mr. Jones’s preparations for his second visit with Dr. Green have allowed him to make an informed choice about pursuing diet (or not, in his case), which most likely abbreviated Dr. Green’s efforts. Mr. Jones was also led to ask for a medication that, in Dr. Green’s judgment, might possibly harm him. The knowledge imbalance between patients and physicians has changed, producing situations in which physicians must learn to communicate with web-savvy patients and harness the power of the most potent source of information in history [1].

In 2005, an estimated 117 million Americans searched for health information on the web, a number that has increased dramatically over the past 10 years [2]. Approximately half of these individuals report discussing the results of their web-surfing with their doctors [2]. Another study found that 80 percent of adult Internet users reported searching for information about their own health [3]. The percentage of each age group that uses the Internet to access health information decreases as age increases [4]. Such individuals also tend to be from more affluent communities and are predominantly women [4-7].

A New Dynamic in the Office

The rise of web-savvy patients alters the power dynamic in the patient-doctor relationship. In the older model of care, physicians served as unchallenged content experts who were called upon to lay out therapeutic plans for patients. Patients were expected to trust their physicians and comply with the prescribed plans. This marked asymmetry simplified communication in the office (inasmuch as it was almost uniformly one-way), but it also led to misunderstandings and paternalistic patient-doctor relationships. Even before the Internet became such a tool, physicians and researchers recognized the challenges in the uneven relationship and began to develop a more patient-centered model of care.

Patient-centered medicine aims to level the playing field in the office so that the patient and his or her caregivers have an active role in the development of a treatment plan. The movement emphasizes understanding a patient's cultural background, lifestyle, health beliefs, and personal preferences as essential to successfully negotiating a plan. Once a patient's concerns and beliefs are understood, a physician can find common ground with the patient and settle upon mutual goals and plans. The rise of patient-centered medicine, which grew in part out of research conducted by family physician Ian McWinney and colleagues, is detailed in *Patient-Centered Medicine: Transforming the Clinical Method* [8]. Physicians who maintain more patient-centered relationships gain higher levels of trust and adherence to therapy from their patients [9-11]. The Institute of Medicine now considers patient-centered care one of the six domains of quality health care.

Patients with Information

The patient-centered model of care offers Dr. Green solutions in treating Mr. Jones. Patients have always come to physicians' offices with varying levels of knowledge of allopathic medicine. Along with cultural background, personal preferences, and prior experiences, a patient's understanding of medical information contributes to his or her health beliefs and expectations for treatment. Before the rise of the Internet, people obtained information from their family members, colleagues, books, newspapers, magazines, and television and tended to trust these sources, despite the fact that they could be remarkably misleading. The Internet simply ups the ante by providing access to a dramatically increased amount of medical information in an easily searchable format.

Patients' ability to become well-informed about their health conditions through the Internet has potential advantages. Greater patient understanding can close the knowledge gap between patients and physicians slightly and thus ease physicians' efforts to achieve common ground. Particularly in cases of chronic disease such as diabetes, where successful treatment requires patients to take an active role in understanding and applying their treatment plans (e.g., diet, exercise, glucose testing), quality information can improve patients' ability to care for themselves. Unfortunately, physicians often make the mistake of reacting negatively to an assertive, informed patient, taking it as an affront to their authority and expertise. Such responses handicap the physician's ability to establish a connection with a patient and can inhibit trust and adherence.

Solutions

In responding to Mr. Jones's statements, Dr. Green should seek further understanding of his patient's beliefs, by saying, for example, "I'm interested by your comment about metformin; can you explain why you believe newer medicines are better for you?" Or asking, "What have you read that led you to say that you cannot make dietary changes?" Dr. Green should ask Mr. Jones where he found the information on which he is basing his beliefs; blogs and Internet forums are far less reliable sources than sites devoted to patient education. Upon hearing about his patient's beliefs, an affirming statement can help generate trust without placing undue support on those beliefs: "I can understand how reading that could lead you to say you do not want to take metformin."

Dr. Green should then share his own beliefs with Mr. Jones, formulating his comments to respond to his patient's specific concerns and needs. If Mr. Jones thinks he will need two medications to control his sugar because his mother is diabetic and she takes two, Dr. Green can describe the natural history of diabetes and its tendency to worsen with time. Alternately, if Mr. Jones wants the newer combination pill because "the latest advances are always better," Dr. Green can explain his concerns about the safety record of new medications, perhaps citing the recent association of rosiglitazone (a compound in the newer drug) with incidence of heart disease in the management of diabetes. Finally, before settling upon a plan, Dr. Green can seek common ground by clarifying their shared goals, "I am impressed by your concern about your new diagnosis, and I assure you that I will strive to help you achieve excellent control of your sugar."

The skills described above are basic communication tools that can help resolve most perceived disagreements between patients and physicians. There is one important skill, however, that is specific to working with web-savvy patients: physicians should become familiar with trustworthy web resources and be able to guide their patients' web surfing. There are many excellent patient-education web sites. With regard to diabetes, for example, Dr. Green could direct Mr. Jones to the National Diabetes Clearinghouse for current information in English and Spanish from the National Institutes of Health.

The rise of the Internet has exponentially increased patients' access to health information, potentially altering the patient-physician relationship by raising the level of patients' medical knowledge (and perhaps their level of misunderstanding). While the Internet is a high-tech tool, the key to communicating with web-savvy patients is remarkably low-tech. A patient-centered approach emphasizes understanding patients' concerns, beliefs, and goals, as well as establishing common ground in the development of a mutually understood plan. Physicians who successfully negotiate treatment plans with their patients will achieve higher levels of trust and adherence in return and increase the likelihood that patients will log onto recommended sites, further improving their understanding and treatment.

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CLINICAL CASE

Is There a Duty to Inform Patients of Phase I Trials?

Commentary by Courtenay R. Bruce, JD, Anne Lederman Flamm, JD, Thomas W. LeBlanc, MD, MA, and Philip M. Rosoff, MD, MA

Andrew, a 15-year-old boy, was diagnosed with acute lymphocytic leukemia. He underwent standard chemotherapy treatments and a bone-marrow transplant, none of which produced remission. No other standard therapies were available for Andrew to try. Dr. Wilson, Andrew's oncologist, knew of a phase I trial of an experimental oncology therapy going on at the hospital where Andrew was being treated. Participants in these types of trials have end-stage cancer and often a prognosis of months to live, criteria that Andrew fit. Phase I trials test the safety of the experimental agent and determine the dosage that will be used in later-phase trials.

Dr. Wilson knew that phase I trials did not aim for efficacy and did not demonstrate very favorable response rates for outcomes such as tumor shrinkage. Yet he felt he should inform Andrew and his family about this study, giving them the option to decide whether or not Andrew would participate. He was concerned that, in presenting this option to them, they may think that he was advocating for Andrew's participation.

Commentary 1

by Courtenay R. Bruce, JD, and Anne Lederman Flamm, JD

In 2007, approximately 10,400 children under the age of 15 were diagnosed with cancer. Of them, 1,545 will die from the disease [1]. Despite these sobering figures, pediatric-cancer survival rates are increasing, most likely as a result of clinical research that includes pediatric-oncology participants in the hopes of finding new therapies.

Ethical Issues

Standard phase I studies are first-in-human trials in which successive cohorts of three to six patients receive increasing doses of an investigational agent to evaluate the drug's toxicity, maximum tolerated dosage, and pharmacokinetics. While investigators may note clinical responses and outcomes, phase I trials are not designed to test efficacy, a target reserved for subsequent phase II testing. Studies estimate only a 4 to 5 percent response rate in phase I cancer trials, which historically used highly toxic drugs with unknown long-term effects; thus, they are typically offered only to patients who have exhausted all established therapeutic options [2]. The combination of toxic drugs, dying subjects, and the low likelihood of direct benefit raises concern that phase I trials subordinate individual participants'

well-being to the interests of science. Phase I studies in end-stage pediatric-cancer patients like Andrew are particularly ethically controversial in light of society's special duty to protect children. Historical examples of serious abuses of children in the name of scientific advancement are experiments in Nazi concentration camps and, in the United States, the infamous Willowbrook study in which investigators deliberately infected institutionalized children with the hepatitis virus [3].

Dr. Wilson recognizes the inherent tension between the scientific purpose of phase I studies and a physician's ethical obligation to promote his patient's best interest. The case does not indicate that Dr. Wilson has direct involvement in the phase I trial to which he may refer Andrew, but, even without such involvement, physicians can face pressure to support research, and that pressure might influence their decision about whether participation is appropriate for a patient.

Promoting patient best interest and enhancing autonomy require physicians to disclose the risks and benefits of participation and nonparticipation. Despite the low likelihood of direct benefit, patients often perceive the phase I option as therapy [4]. The dependent nature of the patient-physician relationship encourages this "therapeutic misconception" inasmuch as the patient trusts the physician's medical judgment and may believe that the physician offers only what is best [5]. Influences outside this relationship can exacerbate therapeutic misconception. The media readily disseminates early favorable research results, and research institutions often advertise trial participation as being a form of treatment or the best chance for a cure [6].

Concern about therapeutic misconception led to recommendations to improve the informed-consent process in order to enhance participants' understanding of phase I purpose, design, and risk-benefit ratio [6]. More recently, however, patients and advocacy groups have disavowed exclusion from research as a means of protecting patients with incurable diseases, arguing that individuals with terminal cancer, not healthy physicians or paternalistic research oversight bodies, should determine whether the risk-benefit ratio is acceptable [7]. Full disclosure throughout the consent process enables prospective participants to make this risk-benefit assessment.

This informed-consent process also includes a discussion of nonclinical benefits. The patient may benefit psychologically from participation by fulfilling the need to gain some control over his or her illness or contributing to society. The patient might derive a sense of hope as well, thinking that if there were no hope, the drug would not be tested [3, 4].

Patients express that participation offers hope even when they understand the trial's purpose. In contrast, when therapeutic options are absent, both patients and physicians often view an alternative to trial participation—palliative care—as giving up. Some physicians are uncomfortable with ceasing curative efforts because this seems contradictory to the role of healer [4, 6]. Nonetheless, information about

alternatives to participation is necessary for the patient to make a risk-benefit assessment. The physician may want to discuss the advantages and disadvantages of both participation and nonparticipation concurrently to mitigate concerns about physician influence. Discussing palliative care within the context of a comprehensive care plan that provides symptom control and comfort while living with cancer, and not just as a transition to dying, may limit the patient's and the physician's apprehension about the topic. The physician may also want to discuss hospice care and its benefits, including pain palliation and provisions for spiritual or social needs of the patient and his family [3].

Because patients have a right to be informed of and make autonomous choices about appropriate care, physicians have an ethical obligation to inform patients who meet eligibility criteria for phase I trials of that option. The information given to prospective phase I participants depends on the physician's involvement in the trial. If the physician is not actively part of the trial, he or she may not be obligated or even able to provide explicit information about its particulars. In all cases, the trial investigator should be the one to present detailed information at the time of enrollment. The referring physician can supply general information about phase I studies and discuss whether participation is an appropriate choice for the patient [2, 4, 6]. The referring physician can also ensure that the consent process contains adequate information and that the patient's choice is voluntary.

Adolescent Assent

Adolescent patients must be able to comprehend the information they receive and to assent or dissent voluntarily to participation in research. Legally, adults are presumed to be autonomous and competent to consent to become research participants, while unemancipated minors are generally presumed to be legally incompetent to consent [8]. In such instances, parents have a legal right to make health care decision in behalf of their child. In this case, although it might be legally sound to confine decision-making powers to Andrew's parents, Dr. Wilson has an ethical obligation to Andrew. In an attempt to reconcile Andrew's interest in autonomy with parental authority, Dr. Wilson should seek Andrew's assent and his parents' permission for Andrew to participate in the trial [3].

To assent, Andrew must have a basic understanding of the study's purpose and procedures and must be able to state whether he wishes to participate or not [8]. Psychological studies have indicated that, by age 14, most minors have attained the cognitive skills necessary for reasoning and decision making [8, 9]. Andrew should demonstrate maturity, understand what is being asked of him, and be able to communicate his thoughts about participation. The physician can seek assistance in assessing a patient's capacity, such as the expertise of a psychiatrist or developmental psychologist [8].

Andrew's assent or dissent must be voluntary, and he should know his assent is being sought independent of parental permission. The tendency for children to defer to their parents can be mitigated by controlling the consent process. Dr. Wilson

might consider talking to Andrew without his parents, or, in their presence, addressing questions specifically to Andrew and encouraging him to speak [8, 10].

If Andrew dissents, it is reasonable for Dr. Wilson to inquire about the bases for his decision. He may be dissenting on grounds of misconceptions that can easily be clarified. Dr. Wilson should also evaluate whether his dissent reflects age-appropriate nonconformity, because a patient's true preferences may be obscured by nonconformist attitudes. If Andrew continues to dissent after undertaking a thorough decision-making process, he is likely demonstrating his true values and preferences [8].

Divergent conclusions between parents and their adolescent can also present ethical challenges. Parents are legally obligated to promote their child's best interests [3, 8, 10]. If Dr. Wilson has reason to believe Andrew's parents are not considering his best interests, he might petition a court to appoint a guardian for Andrew, though guardianship is typically pursued as a last resort when a child lacks an appropriate representative. Dr. Wilson should use his professional judgment in determining whether the parents are competent to contribute to the decision making.

Parents may disagree with each other or their child. Federal regulations, state law, and institutional research policy provide guidance on whether one or both parent(s) must give permission for trial participation. In general, where the child can expect no direct benefit from the trial drug, federal law allows him or her to be exposed to only minimal risk. If Andrew's parents want him to participate and Andrew objects, his objection should be weighed heavily since phase I trials offer little chance of a clinical benefit [8, 10].

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Commentary 2

by Thomas W. LeBlanc, MD, MA, and Philip M. Rosoff, MD, MA

This case raises a number of difficult ethical issues, in both the clinical and philosophical realms. Owing to their complexity, a thorough analysis is impossible in a short commentary; so we will highlight the most salient questions in the hopes that this piece will serve as a springboard for further discussion.

One must begin with some background information about Andrew's condition. Acute lymphoblastic leukemia (ALL) is the most common childhood leukemia, accounting for upwards of 30 percent of all pediatric cancers [1]. Due in no small part to participation of children and their families in organized clinical trials over the last 30 years, it is now a readily treatable disease in the majority of cases, with cure rates averaging roughly 80 percent [2]. Nonetheless, relapse following therapy for ALL remains the second leading cause of cancer deaths in children. Unlike most adults with cancer, the majority of children with cancer are enrolled in a clinical trial. Clearly, clinical research involving pediatric malignancies is of paramount importance. Children enrolled in so-called therapeutic trials derive direct benefits from their participation, ranging from the Hawthorne effect, to positive effects of the experimental therapy [3-6]. Moreover, the clinical research enterprise bestows a social good that benefits future patients.

Andrew appears never to have been in remission, which portends a dismal prognosis. While myeloablation with stem-cell transplant may offer some possibility for long-term survival, patients must be in remission for the best chance of success. At this point, having failed first- and second-line therapies, options for Andrew's care include palliation or participation in another clinical trial (if he is eligible), but neither of these is curative. It is a common misconception that therapeutic clinical trials always seek a cure, so we must be careful to clearly distinguish between different types. In this case, Dr. Wilson feels obligated to inform Andrew about a

phase I trial. This is a very specific subtype of clinical trial and is quite different from the multicenter cooperative studies that led to today's improved cure rates for ALL. Rather, the purpose of a phase I study is "to evaluate [a drug's] safety and identify side effects" [7]. Hence, there can be no reasonable expectation of any direct benefit to a participant.

Unfortunately, it seems that the mere suggestion of a phase I trial as an option lends credence to, or generates a false hope for, a cure or some form of beneficial outcome, especially if it is offered by the treating physician. Dr. Wilson knows (or should know) that such studies aim to collect data regarding safety, pharmacokinetics, and other *in vivo* drug properties, but these details are easily misconstrued by patients and families, regardless of a physician's intentions [8]. Some have termed this false hope for cure the "therapeutic misconception" [9, 10]. In this setting, a phase I study may be viewed as a last-ditch effort for a cure, and can be difficult to refuse when presented as an option. Compared to palliation, which is often perceived by families as "giving up hope," participation in the trial feels like a way to keep fighting. But properly understood, a phase I study stands to yield no such benefit to the subject, and thus cannot rightfully be thought of as a reasonable choice in the quest for a treatment.

The therapeutic misconception presents Dr. Wilson with a difficult dilemma, inasmuch as it may conflict with other physician duties, including the Hippocratic requirement to "do no harm," and its unwritten prescriptive corollary to "do good" for individual patients. It is particularly problematic if a phase I study is pursued at the expense of palliation, or if the study medication hurts the child. One might argue that the bioethical principle of beneficence mandates a "duty to palliate" whenever there is no remaining hope for a cure. Since a phase I study presents no such hope, it might be considered tragic for Andrew to participate in this trial instead of just going home, spending quality time with family and friends, and living out his remaining weeks on his own terms with the help of a home hospice or similar program.

Insofar as this study provides no reasonable expectation for cure, there can be no legitimate duty to inform a patient or family about the phase I study. One might even argue that raising such a study as an option contributes to the fostering of false hope and inappropriate delay of rightful palliation. The simple act of an oncologist's presenting a study as an option commonly leads to the presumption that it will benefit the patient. Yet for phase I studies, there can be no reasonable expectation of *any* direct benefit to the patient, regardless of how promising a new drug or technology might seem. There are too many variables and risks to assume any chance of benefit, and most certainly not a chance of cure. Not surprisingly, pediatric oncologists are conflicted and confused about the nature and role of phase I studies [11].

Unfortunately, even the process of phase I studies can be misleading with CT scans, blood counts, and bone-marrow biopsies often being part of the protocols. If one has no expectation of a tumor response, why should these measurements be a part of the

study? Yet these tests further facilitate unrealistic expectations from participants and confuse families. So if participation delays palliation, one must wonder whether presenting the study as an option is ethical in itself. It would seem that the only ethically reasonable option, then, is to allow participation in phase I studies *only* when rightful and appropriate palliation is also provided and when participants and families fully understand the aims of the trial. This is quite a tall order, to say the least.

On the other hand, if doctors did not enroll their (and others') patients in phase I trials—be they children or adults—we would never be able to gather the vital information about new drugs and treatments that fuels the advance of medicine. Thus, there may be a social duty, if you will, for doctors to offer patients the option of participation in these trials (and for patients to volunteer), even when there is no expectation of individual benefit. While outside the scope of this commentary, this point raises the complex questions of the proper role and societal obligations of oncologists in the clinical research enterprise. Less obvious is the fact that, if the patient-doctor relationship remains intact, any recommendation for treatment or care of a condition must be viewed as both potentially beneficial by (and for) the patient and endorsed by the doctor. Therein lie the major dilemmas which remain unresolved.

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CLINICAL CASE

Establishing Common Ground in a One-Time Patient Encounter

Commentary by Benjamin Levi, MD, PhD, and D. Micah Hester, PhD

Mrs. May took her 4-year-old daughter Emma to Dr. Smith because Emma had a cold. Dr. Smith had not seen Emma before, and asked Mrs. May who Emma's primary care doctor was.

She responded, "I just haven't been able to find a doctor who is right for Emma. I took Emma to a general pediatric clinic 3 weeks ago when she had a rash on her back, and 1 week later we went to an acute-care clinic because she was vomiting and had diarrhea."

Dr. Smith examined Emma and found that she had an upper respiratory infection (URI) that would probably resolve in the next day or so and did not need treatment. He explained this to Mrs. May.

"I think that Emma needs some sort of treatment to help her get over the infection," Mrs. May said. "She is not going to get better without it."

Dr. Smith told her that if the condition did not resolve in a couple of days, she could bring Emma back in or give him a call and he would reconsider.

At the end of the visit, he asked, "Can we schedule Emma for a follow-up well-child visit in a few months?"

"Let me think about it," said Mrs. May. "I am not sure that we are ready to commit to you as our primary pediatrician quite yet."

Two weeks later, Dr. Smith saw Mrs. May and Emma at his office, but they were visiting one of the other doctors, Dr. Moore. Dr. Smith asked him about the visit.

"Emma had another URI," said Dr. Moore. "Her mom was concerned so I gave her some antibiotics for Emma to take."

"Were you able to set up a follow-up visit?" asked Dr. Smith.

Dr. Moore replied, "Mrs. May said that she will bring Emma in next month for a well-child visit."

"You know Mrs. May probably wants you as her primary provider because you will

do whatever she wants you to for Emma,” said Dr. Smith.

“I don’t think that it is especially harmful to give a kid some antibiotics, even if in all likelihood she has a viral infection,” said Dr. Moore. “Anyway, I was able to get Mrs. May to agree to a follow-up visit so that Emma is going to receive care from me rather than from random physicians. I think that it was a small compromise to make in order to ensure a better level of care for Emma.”

Commentary 1

by Benjamin Levi, MD, PhD

It is not uncommon within a group practice for clinicians to disagree about treatment regimens. Medicine is far from an exact science. Clinical decisions are often influenced by a clinician’s training, past experiences, and his or her propensity to accept uncertainty and risk [1]. What makes this case problematic from the standpoint of ethics and professionalism is that it raises questions about what constitutes *medically necessary*, whether it is justifiable to do something wrong in the pursuit of a (presumed) greater good, how professional standards are determined, and what are the limits of patient and parental rights.

First, however, a variety of process and communication issues warrant some comment. We know from both research and personal experience that how a message is *delivered* can make a great difference in how it is *received* [2]. When Mrs. May expresses her view that without some sort of treatment Emma is not going to get better, Dr. Smith could have agreed and then gone on to explain: “I think you’re right that without proper treatment it’s going to take longer for Emma to get better. The question is, what’s going to help her most? Everything I see today suggests that Emma has a viral infection, and, while they tend to be less serious than bacterial infections, we have fewer medicines to treat them. Antibiotics, for example, wouldn’t do anything for her other than possibly give her diarrhea, and of course cost you money. What we can do to help her feel better, though, is give her anti-inflammatory medicine that will decrease many of her symptoms.”

In this way, Dr. Smith positions himself as an ally of Mrs. May and Emma, rather than the gatekeeper to desired (and forbidden) medication. Further, Dr. Smith can validate Mrs. May’s concern: “You’re doing the right thing. It’s *your* job to worry, and it’s *my* job to help you figure out what to worry about. If you’re not going to worry about your daughter, who is? Now, let me tell you about the things that would make me worry—the red flags for a bacterial infection or serious medical condition.”

Building Patient Trust

A significant part of a physician’s job is to provide a context for patients and parents to understand what various signs and symptoms mean. Many people don’t know the difference between a bacteria and a virus, much less how antibiotics work. It is also helpful to reinforce that a physician should always have a good medical justification for what he or she does, since virtually any treatment has potential adverse effects.

Dr. Smith might also remind Mrs. May with a smile that much of the time in pediatrics, children get better despite our efforts rather than because of them.

Such approaches often help parents place their concerns in better context. That said, there are some parents who will not be satisfied by anything short of receiving the medical treatment they think is appropriate. When the parent is also a health care professional, this can be especially challenging, particularly if he or she fails to appreciate the impact that emotional attachment can have on professional judgment. Sometimes, though, what is really at issue is a lack of trust—the *sine qua non* of effective medical practice. Parents and patients invariably bring expectations to their clinical encounters, shaped by previous interactions with doctors—some good, some not. Good physicians know that, in the face of skepticism, one builds trust through clear communication, transparency, and treating others with respect, and with some individuals it just takes time. But if at the end of the day a parent or patient *insists* on being unreasonable, then it is unlikely that reasoned approaches of any sort will have a significant effect.

We do not know how amenable Mrs. May might be to the approaches mentioned. But the description we have suggests that when she disagrees with a physician's medical judgment, she will reject it. And this is her prerogative—in most cases. Parents have wide discretionary authority in how they raise their children, and (barring abuse or neglect) they have the right to reject others' recommendations [3]. Such rights of refusal are termed *negative rights* [4, 5]. They may be contrasted with *positive rights*, which entitle an individual to receive something from another party—be it property, a service, or some process (e.g., schooling or due process of law). In the context of medical care for children, parents have the negative right to reject sound medical treatment—such as vaccines, tests for tuberculosis, medicine to treat acne—so long as doing so does not constitute medical neglect. But parents do not have the corresponding positive right to demand medically inappropriate treatment [6].

Medically Indicated Treatment

What ultimately constitutes medically indicated treatment is determined by the professional judgment of qualified physicians [7]. Medical licensing boards and society at large expect that physicians can provide medical justification for their treatment decisions. It is on this basis that society grants exclusive treatment privileges to physicians. This is not to say that what counts as medically indicated is always clear-cut. But in the case of prescribing antibiotics for what is clearly a viral infection, Dr. Smith is on solid ground in being critical of Dr. Moore. In fact, one could argue that such criticism is required, insofar as the medical profession is expected to be self-policing in maintaining its standards and codes of conduct.

Examining the Prescribed Treatment

Though seemingly minor, Dr. Moore's treatment decision is actually problematic on many levels. First, the unnecessary use of antibiotics contributes to the growing problem of antibiotic resistance [8]. Second, it unnecessarily risks adverse effects

associated with antibiotic use—from *Clostridium difficile* disease to Stevens-Johnson syndrome—when there is no need to incur these risks. Such unwarranted treatment puts the prescribing physician (and his or her practice) at legal and financial risk should a serious adverse event occur. It reinforces the parent’s inappropriate request, setting a precedent for future requests—with full knowledge that the average 4-year-old child has six to 10 upper respiratory infections per year. By validating the parent’s unreasonable expectations, such prescribing creates the potential for conflicts with other physicians who may subsequently provide medical care to Emma. Finally, Dr. Moore’s treatment of Emma is deceptive insofar as it indicates (disingenuous) agreement that viruses should be treated with antibiotics.

Is it worth incurring these potential costs to establish a medical home for Emma? If Mrs. May is truly an unreasonable person, it’s not at all clear that future encounters are likely to reach conclusions that are any more medically appropriate. There are some parents and patients whom we can neither help nor appease. But if Mrs. May is open to reason, then why not begin the relationship by appealing to her good sense? With effective communication skills and a respectful and supportive attitude, many seemingly intransigent parents and patients “come around.” Conversely, many treatment decisions physicians make for patients have room for negotiation and can accommodate at least some individual preferences. Making one’s reasoning transparent and remaining open oneself allows for medical decision making that is professionally defensible, intellectually honest, and reasonably flexible.

Communication with Colleagues

How to best approach colleagues with constructive criticism of their clinical decisions is an entire topic unto itself. That said, the following ideas offer some guidance:

- Such conversations are part of a healthy relationship.
- Many factors contribute to how another person will receive your efforts. Among them are timing and location; tone and choice of language; and ability to nurture and convey a sense of openness—where openness involves not only suspending judgment, but being willing to learn (and perhaps accept) others’ perspectives and interpretations of the issues at hand.
- Be prepared for the unexpected, both in the form of a breakthrough and defensive response.
- Find cooperative ways of communicating that do not bludgeon people, recognizing that yours is but one of many windows on the truth. Sometimes this can be done simply by stating your understanding of the situation or inquiring whether there’s something you’re missing. It can be useful to introduce independent standards—e.g., professional codes, hospital policies, peer-reviewed publications, etc. In fact, reaching agreement about what might serve as an independent standard could itself become both a means and a goal of one’s conversation.

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Suggested Reading

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Commentary 2

by D. Micah Hester, PhD

To analyze ethical issues that arise in the story of Dr. Smith, Mrs. May, and Emma, it's useful to look at the scenario in three parts—roughly following the chronology as given. What the analysis shows is missed opportunities by Dr. Smith and questionable judgment by Dr. Moore.

In the initial encounter between Dr. Smith and Mrs. May (we do not hear from 4-year-old Emma), we learn that Mrs. May is concerned that Emma has a cold and that Dr. Smith is interested in whether Emma has a primary care physician. Such an exchange is not unusual, but we should note that they begin their dialogue in two different places. Mrs. May, looking for a response to her child's illness, initially finds an inquiry into her relationship to pediatric care. Nothing is made of this in the scenario itself, but it is worth pausing to recognize that this kind of exchange can undermine trust. Rather than reflecting Mrs. May's concern—an indication that he is

listening and that “we are in this together”—Dr. Smith turns to his own (well intentioned, I suspect) concern for good primary-care continuity.

Given Dr. Smith’s line of inquiry, it is striking that, when Mrs. May states that she has not “been able to find a doctor who is right for Emma,” Dr. Smith follows by asking about other recent visits to the doctor. This is a missed opportunity. Crucially, Dr. Smith does not ask what seems to me to be the reasonable follow-up: “What kinds of things are you looking for from your daughter’s primary care physician?” This question allows Dr. Smith to elicit Mrs. May’s story—at least as it relates to her child’s health care—and provides the opportunity to develop common ground *before* the exam and diagnostic discussion occur. Again, we quickly see two incidents in the brief communication where Dr. Smith’s responses are not those of someone who is listening carefully and engaging directly the concerns of the patient’s mother.

Part two of this scenario describes an exchange about treatment for Emma’s condition. Here again, Dr. Smith loses an opportunity to connect. While acknowledging that Emma has a URI, Dr. Smith indicates it is not something that needs treatment. Mrs. May disagrees. Rather than providing a “wait and see” response, Dr. Smith could have stopped here to acknowledge that Emma is, in fact, ill. This simple acknowledgment can establish a connection with Mrs. May, who clearly worries about her child’s health (as evidenced by the several trips to a physician she has made in the last few months). Dr. Smith, then, could continue by moving from this common point to explore why Mrs. May believes Emma will only get better with treatment. Through this he may be able to help distinguish actions that can help relieve troubling symptoms from “treatment” intended to cure underlying conditions. If he is correct that the URI is viral in origin, a “curative” treatment may not be available, but he should also not allow Mrs. May to have the impression that “no treatment” equals “nothing can be done to help your daughter.” Our language often betrays us, and we do not work carefully to make sure we are understood and that our patients and parents are understood as well. Had a conversation about what can be done occurred, Dr. Smith’s comment about reconsideration if symptoms did not subside in a few days could be taken in light of having done *something* rather than nothing. Part two ends with a reprise of the primary care physician inquiry, and, again, Dr. Smith drops the ball. When Mrs. May states she is “not sure that we are ready to commit to you as our primary pediatrician quite yet,” Dr. Smith should react to the comment not as if it ends the conversation but as an invitation to explore what Mrs. May is looking for in a primary care physician and to reassure her that he has the goal of providing the best health care for Emma—a goal they share.

Behind the exchange between Dr. Smith and Mrs. May resides a fundamental ethical tension in pediatrics—given the medical expertise of physicians, how far should parental authority be allowed to operate? Or put another way, who gets to decide what is best for the pediatric patient, and why? Assuming that children (especially 4-year-olds) do not have decisional capacity for such medical considerations, others must speak in their behalf. Our society strongly supports a broad scope for parental authority, and yet parental demands for treatment in the face of physician

disagreement create a tension that challenges this authority. Dr. Smith, if correct in the diagnosis (and that is still questionable), is right not to provide antibiotics, but, as noted above, no antibiotic treatment is not the same as no treatment at all.

The scenario's final section describes an exchange between Dr. Smith and his partner Dr. Moore after Mrs. May brings Emma to see Dr. Moore some weeks later. Here, a number of ethical issues arise. First, while it may be natural curiosity on Dr. Smith's part, he should, in fact, refrain from asking about another physician's patient. Unless he is consulted, Mrs. May's current visit to Dr. Moore establishes a relationship exclusive, not inclusive, of Dr. Smith. Here, Dr. Moore errs too, for, even if asked by a partner, he should not give confidential information about his patient to a (now) unrelated party. While it is not uncommon for colleagues to have such conversations, sharing an office is not equivalent to sharing patients—if it were, Dr. Smith would not need to distinguish between Mrs. May's choosing him or Dr. Moore as a primary care physician. Mrs. May appears to be making a distinction, even within the same office, and part of the importance of the distinction is the trust she places in the person chosen as the primary care physician. Confidentiality is an expected extension of that trust. Further, it is clear that Dr. Smith and Dr. Moore have more to talk about concerning their own professional relationship.

One more issue remains. Dr. Moore, unlike Dr. Smith, provides antibiotics to Mrs. May. Given that this is a recurrent (or sustained) URI within 2 weeks of the previous visit, medication may, in fact, be indicated, though it would seem that the intent in prescribing antibiotics, according to Dr. Moore's own comments, is not so much about Emma's present illness but her long-term care. Should medications be used for reasons other than to cure a disease or alleviate symptoms? Dr. Moore is simply wrong in saying that no harm comes of giving an antibiotic to a child who does not need it, even though he is certainly not alone in this belief and practice. Medications are not benign and should be directed at signs and symptoms, not the psychology of the patient's parent. While Dr. Moore's desire to provide long-term continuity of care for Emma is laudable, the ends, here, do not justify the means. Emma may need antibiotics, and to that end they should be prescribed, but Dr. Moore's rationale does not speak to alleviating infection as their intended purpose, and that is troubling.

This case presents missed opportunities and misplaced intentions; it demonstrates the need for a good preventive ethic that can help mitigate, if not completely avoid, troubling issues that surface when careful communication and forethought are not marshaled.

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ON CALL

When Patient and Physician Disagree on Patient's "Best Interest"

Mr. A is making his first visit to Dr. M, an oncologist, because of debilitating bone pain and severe constipation. For the past year, he has been treated for cancer of unknown origin by a state-licensed naturopathic physician whom he has seen extensively over the years for what Mr. A explains were a variety of autoimmune diseases and infections. Despite this therapy, the cancer has progressed to an advanced state with multiple vertebral metastases, including a large tumor in his cervical spine which required emergency surgical decompression 3 weeks prior to his visit to Dr. M. Before the hospitalization for surgery, Mr. A was not under the care of a medical oncologist. Mr. A is aware that he may need additional therapy but is worried about the toxic effects of chemotherapy and radiation.

Mr. A was told to see Dr. M by a close friend who explained that Dr. M "is the kind of doctor who treats the whole person." In his initial interview with a clinic nurse, he explains that he has suffered all his life from what he believes is heavy metal poisoning. His father was a dentist, and the family was exposed to large amounts of heavy metals which, Mr. A believes, weakened their immune systems and gave them cancer and neurological deficits. Two years earlier he had a large set of silver fillings removed by a dentist who botched the procedure, Mr. A says, exposing him to a high enough dose of silver to precipitate his current disease.

To make matters worse, Mr. A has an adult son who has autism, which Mr. A believes was caused by heavy metal "poisons" that accompanied his childhood vaccinations. His son does not work or help out around the house. Mr. A has received some support from a neighbor but he has been mostly on his own throughout this illness. The nurse listens carefully and makes brief notes about Mr. A's medical and social history, but Mr. A becomes increasingly frustrated throughout the conversation, as though his view is not being heard.

When Dr. M enters the room he finds an ill man who appears to be in marked discomfort, despite receiving moderate doses of narcotic analgesia. They begin by reviewing Mr. A's medical chart, including a CT scan of his spine that shows multiple large masses. There is no record of his treatment by the naturopath. Dr. M sits down, faces Mr. A, and begins by addressing his symptoms. He prescribes ethylene glycol as a laxative to relieve Mr. A's constipation, but the patient refuses the prescription initially, saying he has read that it is toxic. The doctor explains that it is cancer that is killing him, not the drugs. The patient mentions a friend who wasted away while on chemotherapy, and as they talk about what might have caused her death, Mr. A confides his fears to Dr. M and cries. Dr. M refers Mr. A to a pain

specialist and recommends that he begin chemotherapy and radiation the following week, after he has a few more days to gain some strength but before too much time passes. Mr. A tentatively agrees, but Dr. M is afraid that he will not return for follow-up.

Questions for Discussion

- Should Dr. M try to convince his patient to undergo chemotherapy?
- Does Mr. A's decision to refuse treatment meet the requirements for adequately informed consent or refusal?
- Should physicians engage beliefs and practices that do not agree with their medical judgment as a means to securing patient adherence to recommended treatment?
- What can help bridge the gap between the belief systems in conflict here?
- If Mr. A chooses not to show up for additional treatment, does Dr. M bear any further responsibility?

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Commentary by the AMA-MSS Committee on Bioethics and Humanities

This case is one that students will begin to see more and more often as naturopathic medicine increases in popularity across the country. Such cases address the conflict that often arises between respect for the patient's rights and autonomy on the one hand, and, on the other, the physician's judgment regarding what is in the patient's best interest. The situation is also one in which the patient's decisions may have a substantial impact upon the life of another who is dependent upon the patient for support.

Should Dr. M try to convince Mr. A to undergo chemotherapy? The answer to this depends in large part on the probable outcome of the chemotherapy. The possibility of a miracle cure of extremely invasive cancers always exists; however, in this case we should consider less optimistic outcomes, inasmuch as these pose the more difficult questions. If we consider that the cancer is unlikely to be cured, two decisions must be made. First, would chemotherapy prolong the patient's life enough to ensure that his affairs are in order and that satisfactory care arrangements are made for his son? Second, would chemotherapy decrease Mr. A's pain enough to allow him to enjoy the remaining time with his son more than he now can? If the answer to either of these questions is yes, Dr. M should attempt to convince the patient to undergo chemotherapy. We must not forget, however, that Mr. A retains his right to refuse treatment, despite the possible benefits that receiving chemotherapy could have for his remaining life and his son's future care. Chemotherapy should only be undertaken with Mr. A's fully informed consent.

For consent to be adequately informed, the patient must have an understanding of the risks and benefits of treatment—in this case undergoing chemotherapy—and of refusing it. In theory, true informed consent can never be reached, since there is no

way to predict exactly what side effects the patient will experience, how long he will survive, what his quality of life will be under either alternative, and what other procedures he may have to undergo in addition to the planned therapy. At best, informed consent is an educated guess at what is most likely to happen during the course of treatment, but it is by no means comprehensive or exact.

For our purposes in the clinic, informed consent is defined as patients' understanding the treatment goals, possible outcomes (including death and disability), side effects, and other conditions they may face as a result of undergoing treatment. This should not be just an agreement to undergo therapy but an understanding of the good and the bad things that can happen once treatment is initiated. It should be made clear to patients that they can choose to discontinue treatment at any time, should they want to do so (after being adequately informed of the pros and cons of not continuing).

This case presents another interesting conundrum: should the effects of treatment or lack thereof on Mr. A's adult son be included in the discussion of informed consent? One could make the case that this is irrelevant because it is not a direct effect of the patient's treatment regimen and, therefore, should not affect informed consent. At the same time, the son will be indirectly affected by his father's treatment decision and on that basis it can be argued that some consideration be taken for the son's well-being. In fact, Dr. M might want to suggest to Mr. A that chemotherapy could perhaps extend his life enough for him to arrange for his son's future care.

To what extent should Dr. M stay involved in Mr. A's care if Mr. A decides to continue with naturopathic treatment in conjunction with Dr. M's recommended treatment? This depends on the nature and extent of the naturopathic treatment Mr. A wishes to pursue and the compatibilities of the naturopathic treatment (if known) with the allopathic treatment.

If Mr. A is certain that he does not wish to undergo medical treatment with "toxins," it is not necessarily Dr. M's job to convince him to do so. As physicians we are obliged to provide as much information as possible in a truthful manner so that the patient can make an informed decision. But we must also respect the patient's autonomy. If, after demonstrating what appears to be an understanding of the treatment, the patient chooses not to undergo the therapy, we should not try to force the issue. We should, however, remain available for consult or further care should the patient change his mind and choose at any time to pursue allopathic medical treatment.

Many patients want to try a combination of naturopathic and allopathic treatments. This can be done if the combination of treatments is not deemed undesirable or antagonistic to either protocol. Examples of therapies that are compatible with allopathic treatment include, but are not limited to: aromatherapy, stretching and exercise therapy, and some macrobiotic diets. Determining whether a naturopathic treatment may limit the effectiveness of the allopathic therapy—or even pose dangerous side-effects—is not easy and must be done on a case-by-case basis.

With the idea of combination therapy in mind, Dr. M should consider the fact that many naturopathic treatments can be extremely toxic. Herbal kelp supplements, for example, have been found to contain levels of arsenic higher than the Food and Drug Administration tolerance level [1]. Conversely, discussing the development of drugs from plant extracts may prove enlightening to the patient, especially in this case where “toxins” are a major concern of Mr. A’s and a potential barrier to his receiving allopathic therapy. Dr. M could point out that numerous cancer therapies in common use were initially isolated from naturally occurring compounds; paclitaxel, for example, was discovered in extracts of the Pacific yew tree. While a discussion of this type should not necessarily be used to convince Mr. A to undergo chemotherapy, it can inform him of the parallels between the mechanisms of naturopathic and allopathic treatments (e.g., both may contain toxins, but one is perceived to be less injurious to the body than the other, despite their similar structure and mechanism of action).

Prevention of the patient’s suffering must be of paramount concern, not only to alleviate his current suffering but also to prevent similar tragic situations in the future. Continuity of care and proper record-keeping on the part of the naturopathic physician will help Dr. M evaluate possible drug interactions and expedite treatment should Mr. A choose to undergo allopathic treatment with chemotherapeutic agents. It should also be remembered that, in this case, the naturopath is a licensed professional and is liable for the diagnosis (or misdiagnosis) of the patient’s condition just as an allopathic physician is. Physicians’ responsibilities to the patient are the same whether they utilize naturopathic, osteopathic, or allopathic diagnostics and treatments.

Finally, should Mr. A choose not to undergo chemotherapy, the physician’s office should offer to provide any information he requests about the treatment. Mr. A is a legally competent adult who has the right to make his own decisions regardless of the anticipated outcome. Mr. A is also his son’s (presumed) legal guardian since the latter is not capable of caring for himself. While the effects of Mr. A’s decisions on his son should be considered, the son is not the patient. Perhaps a trusted third party should be appointed by Mr. A to make sure his son’s best interest is seen to, should Mr. A become too debilitated to provide care. Recommending this action is by no means a mandatory part of Dr. M’s duty to his patient, but would be the best option available unless Mr. A is able to complete the necessary arrangements for his son’s long-term care before he is incapacitated. Even if long-term care is arranged, Mr. A’s appointing a guardian to make future decisions regarding his son care is recommended over leaving them to an unaffiliated third party.

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Call to Readers

To encourage responsible ethical debate and critical thinking, the AMA-MSS Committee on Bioethics and Humanities invites medical students to submit written responses to this case. Responses should be 800 words or fewer and should be sent as an e-mail attachment to oncall@ama-assn.org. Readers who submit comments must identify themselves by name, date of birth, and medical school so that their medical student status can be verified, but they may use a pseudonym as a signature to their comments. Letters will be published at the discretion of the AMA-MSS Committee on Bioethics and Humanities. Additional announcements will be posted on the committee's website: <http://www.ama-assn.org/ama/pub/category/15539.html>.

Medical students who wish to submit cases and commentaries on upcoming *Virtual Mentor* themes should visit the [On Call Guidelines for Submission](#).

The facts of this case have been changed so that it does not describe the actual experience of the student-author or of a specific patient. Resemblance of the resulting case to the actual experience of a specific student or patient is coincidental.

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MEDICAL EDUCATION

The Patient's Voice in Medical Education: The Family Centered Experience Program

Arno K. Kumagai, MD

Within the intimacy of the patient-doctor relationship, there is a deceptively simple but profound interaction: one human being uses his or her training, knowledge, and skills to alleviate the suffering of another. Profound, but not simple. Misunderstandings and mistrust abound.

“He’s angry and noncompliant.”

“My doctor’s a quack.”

“She doesn’t seem to care what happens to her.”

“My doctor never listens to me.”

Difficult clinical interactions may arise in part from problems in communication, but that’s not the whole story. An even greater barrier to common understanding exists. Patients and doctors often see the same thing—the problem with which the patient is afflicted—from two very different perspectives. For doctors, it is a *disease*, a physiological disturbance that can be understood and treated through biomedical theories and their applications. For the patient, it is an *illness*, the subjective experience of being sick [1]. These two perspectives are frequently expressed in very different languages: the language of disease is dry, scientific, statistical, rational, and impersonal; the language of illness is intensely personal and individual and expresses itself in terms of discomfort, suffering, and loss. American essayist Susan Sontag—herself a breast cancer survivor who ultimately succumbed to lymphoma—once wrote:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place [2].

Modern medicine has become increasingly focused on treatment of chronic illness. Providing this care effectively requires an ongoing collaboration between the patient and doctor to which each brings his or her expertise. The doctor’s expertise is conferred by years of study and training; the patient’s consists of the “lived expertise” of having a chronic medical condition. At the University of Michigan, we believe that an essential part of physician training is an understanding of, and

openness to, the patient's perspective, and through the Family Centered Experience (FCE) we hope to provide temporary entry to this "kingdom of the sick."

Family Centered Experience

Launched in the fall of 2003 as part of a new medical school curriculum, FCE is a required 2-year course in which pairs of first-year medical students are matched with volunteers in the community who have serious or chronic medical conditions [3-5]. Volunteers are not only diverse in their clinical conditions, but also in race, ethnicity, gender, sexual orientation, family structure, and educational and socioeconomic background. During the first 2 years of school, students visit the volunteers' homes for a series of conversations based on different themes pertaining to the experience of illness, such as the impact of illness on the self and family; the relationship between patients and doctors; receiving bad news; stigma and illness; and resources and obstacles in accessing and receiving health care. Following each visit, students meet in groups of 10 to 12 with a clinician-educator to discuss observations, thoughts, and insights from their visits. To foster and maintain a safe environment for discussions of highly personal or emotionally charged issues, the groups and their instructor remain the same throughout the 2-year course.

The basis of the FCE is the stories that individuals and families tell of illness and its care. Stories are arguably the most powerful means that human beings have for passing down wisdom gained through struggles, challenges, and experience, and the FCE wishes to harness this power to enhance empathy and transform perspectives of physicians-in-training toward more patient-centered, humanistic clinical practice [4]. We believe that the power of these stories derives from their ability to stimulate both affective and cognitive learning (to touch the heart and the head) and to link with fundamental social and psychological processes: self-reflection, perspective-taking, and identification with another individual who is different from oneself [4]. Studies of students in the program suggest that the knowledge they gain from their conversations with volunteers differs from that acquired through traditional lectures or textbooks; it is personal, highly individualized, and rooted in specific social and familial contexts [3, 6]. Students learn to treat patients as individuals and not merely as diagnoses and test results.

Among the several essential features of the FCE are (1) the establishment of a long-term relationship of trust and rapport between medical students and volunteers; (2) a place of safety and support in which students may discuss their thoughts and impressions with a small group of peers; and (3) the close relationship between students and clinician-educators who serve as advisors, mentors, and role models of humanistic care. In this learning environment, there is also a major shift in the roles of faculty and students from the traditional "top-down," expert/novice model to one that respects the personal beliefs, values, perspectives, and experiences each individual brings into the classroom. In essence, the small groups are engaged in truly collaborative learning—from their volunteers, instructors, and each other. Interestingly, the impact of these discussions on the instructors themselves has been profound. In one study, the FCE instructors described being continually inspired by

their students' idealism and reported that interactions with students had led to great personal and professional growth and development [7].

Despite the best intentions and effort, challenges still arise. Some students and volunteers have difficulty talking about suffering, death, and dying; some students are skeptical about learning such “soft” or “touchy-feely” subjects; other coursework and exams make competing demands; and the pace of medical school often discourages taking time for quiet thought and reflection. We encourage students to address these and other challenges in the small groups, where, instead of being passive recipients of knowledge, they become active agents in their own learning.

From FCE to Good Doctoring

How do these activities help train doctors to handle difficult clinical situations? We believe that by adopting a clinical approach that validates the patient's perspective and experiences and incorporates a critical regard for the assumptions one makes when encountering someone who is different from oneself, students learn to avoid some of the pitfalls and misunderstandings that arise between patients and doctors. Furthermore, by assimilating lessons learned about breaking bad news and the stigma of illness and by expressing compassion for the true experts—those living with illness—we may tailor our care to fit the specific interests and expectations of those in need. We may learn that the seemingly difficult patient may be reacting to a lifetime of mistreatment and humiliation; the noncompliant patient may not be taking medications due to a lack of clear explanation or insurance and financial means; and the apathetic patient may be distracted by other, equally important issues (e.g., losing a job or home, worries about safety in a violent relationship, concerns about keeping his or her children healthy) and cannot give sole attention to our recommendations and instructions. By listening, we learn. Through thoughtful reflection and empathic identification, we may both treat and heal.

Brazilian educator, Paulo Freire, has described teaching as the practice of freedom [8]. The purpose of the Family Centered Experience and similar programs is not to teach compassion or idealism. These are qualities that beginning medical students have in abundance. The purpose of these efforts is to use stories and conversations, as well as reflection and discussion, to allow each student to fashion his or her own way of working with human beings. At the heart of medicine lies the notion of justice: to treat patients as individuals with all of the richness and complexity that each possesses as a human being. By rehumanizing medicine, we may work with, rather than against, our patients in relieving suffering and providing care.

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JOURNAL DISCUSSION

Are There Blueprints for Building a Strong Patient-Physician Relationship?

Scott B. Grant

Fredericks M, Odiet JA, Miller SI, Fredericks J. Toward a conceptual reexamination of the patient-physician relationship in the healthcare institution for the new millennium. *J Natl Med Assoc.* 2006;98(3):378-385.

Although much has been written about the patient-physician relationship, perhaps the most fundamental question is whether or not a good relationship even matters, and, if so, what can physicians do to enhance its quality. Fredericks et al. studied the impact of the society, culture and personality (SCP) model, the impact of the socially meaningful interactions (SMI) model, and the institution of the family upon the patient-physician relationship [1]. Their analysis identifies reasons why, ultimately, a good patient-physician relationship does matter.

Fredericks et al. begin by assuming that a good patient-physician relationship is worthwhile only if it positively affects the patient in a meaningful way. Berry et al. documented that patients' trust and commitment to their primary care physician were positively associated with adherence, and that adherence and commitment were both linked to healthy eating behavior [2]. Others have shown that trust in physicians improves outcomes and increases patient satisfaction, compliance with a medical regimen, and adherence to a healthy lifestyle (e.g., healthy eating behavior) [2-10]. These positive effects could be quite substantial, given that about 40 percent of deaths are caused by modifiable behavior, including poor diet, physical inactivity, substance abuse, and poor strategies for coping with stress [2].

Patients look for several characteristics when choosing and developing a good relationship with a physician. Fredericks et al. posit that physician empathy is the most important trait, saying that "the good doctor cares about the well-being and feelings of the patient, and the patient knows" [11]. Berry et al. suggest that the doctor's ability to gain the trust of the patient is most important [2]. Physicians obtain patients' trust and convey respect by listening carefully to them, gaining knowledge about them, explaining issues clearly and forthrightly, and treating them as partners in their own care [2]. Other virtues patients seek include availability, benevolence, compassion, competence, honesty, integrity, knowledge, reliability, respectfulness, sincerity, and understanding. All of these attributes lead Berry et al. to the conclusion that the patient-physician relationship is a key component in the delivery of high-quality health care [2].

Fredericks et al. isolate, operationalize, and interpret major models of the relationship that bear upon the educational practice and decision making of today's physicians [1]. They assert that there is a crisis in the patient-physician relationship, with several contributing stressors—the mass media, managed care, malpractice litigation, medical errors, direct-to-consumer advertising, availability of online health information, e-mail communication between patients and physicians, access to pharmaceuticals online and across U.S. borders, and use of complementary and alternative medicine [1]. Fredericks et al. also mention the effects of escalating health care costs on patients and physicians. Implicit in the managed-care stressor is the diminishing amount of time physicians have to spend with patients. Given that the average physician visit is between 15 to 20 minutes, many patients feel that their doctor is rushing and that they do not have time to ask questions and get answers or describe all of their symptoms and concerns. Together these stressors can contribute to a lack of trust, understanding, and loyalty between a patient and a physician, and they can prompt doctors to become closed, defensive, and dissatisfied in their careers.

Fredericks et al. briefly discuss two proposed solutions—the hospitalist movement and concierge medicine—but then quickly turn to the SCP model and SMI for guiding future improvements. The SCP model assumes that the genetic basis of personality is transformed into the finished product—the adult person—via a learning process in a social environment [1]. In this environment, the value system of a culture is internalized [1]. In other words, each patient's personality develops through a combination of nature and nurture through socially meaningful interactions (SMI). Fredericks and colleagues then submit that “the quality of socially meaningful interaction will determine to a great extent the effectiveness of healthcare delivery since it has significant impact on diagnosis, treatment and outcome of patient care” [11].

Under the SCP model, several patient factors (social class, age, race, ethnicity, and family background) influence the patient-physician relationship and may also affect health care access, utilization, quality of care, or personal definitions of health [1]. Other factors that are important but were not mentioned as part of the SCP model are gender, environment (urban, suburban, or rural), religious background, and insurance status. Betancourt asserts that physicians must become culturally competent to deliver excellent care [12]. Doing so according to the SCP model involves the physician's taking into account the background and sociocultural context of the patient.

The patient's family also influences the relationship. “The sick role, health behavior and illness behavior are all developed in the socialization process in which the family is the most basic socializing agency in any society” [13]. Along with instilling health and illness behaviors, families also provide end-of-life care, experience caregiver burdens, and may seek long-term care placement of their relatives. Despite this integral family role, many physicians are reluctant to discuss death and dying with patients and their families. Yet, Emanuel et al. note that close to 90 percent of

caregivers (e.g., the family) felt death and dying discussions were not stressful, and almost 20 percent found them helpful [14].

In response to these multiple influences on illness behavior, Fredericks and colleagues recommend the participatory decision-making (PDM) model—also known as shared decision making—as the framework for the patient-physician relationship. With a goal of improving patient understanding, involvement in decisions, and outcomes, the participatory decision-making model supports patient autonomy and restrains physician paternalism [1]. One study of race, gender, and partnership in the patient-physician relationship concluded that all patients prefer participatory visits; patient satisfaction was tightly correlated with PDM score for all patients, regardless of patient ethnicity [15].

If patients are to participate in decision making, they must have at least a lay person's understanding of the evidence upon which the physician is basing his or her clinical recommendation. Communicating this evidence is not always easy for physicians; using the PDM model requires them to (1) understand the patient's experience and expectations, (2) build the partnership with empathy and trustworthiness, (3) be able to convey the evidence and uncertainties in a way that makes sense to the patient, (4) present the recommendations and the rationale behind them, and (5) check the patient's understanding and agreement [16].

In strong relationships, physicians are able to identify and respond to the patient's unvoiced desires [1]. Half of all primary care visits include one or more clues, and studies show that nearly 10 percent of all patients have something they want to ask their physicians but don't [17, 18]. One topic patients wish their physicians would raise is prescription-drug costs. In one survey, 35 percent of patients who avoided medications because of cost never discussed the topic with their doctors, and in those cases, 66 percent of the physicians did not ask about their patients' ability to pay for prescriptions [19]. When drug costs were discussed, 72 percent of patients found it helpful [19]. Clearly costs associated with health care services and drugs can impact the patient-physician relationship.

Despite its many valuable lessons and insights, the Fredericks et al. article misses several key points. In the brief discussion of medical error, the word “apology” appears once, despite the fact that disclosing errors, offering heartfelt apologies, and providing just compensation have been shown to satisfy patients, reduce litigation, and, in some instances, decrease malpractice premiums [11, 20]. Likewise, Fredericks et al. give insufficient attention to patient counseling, the informed-consent process, and patient preferences in shared decision making. These difficult communication tasks take on greater significance when there is clinical uncertainty, a situation in which the patient's values and attitudes become even more important. One long-standing obstacle to a good patient-physician relationship is the power imbalance between the two parties, yet Fredericks et al. do not suggest how to address this concern.

Obviously, the quality of the patient-physician relationship is critical to outcomes, patient satisfaction, compliance, and the ability to make lifestyle changes. Physicians must be aware of the many stressors inherent in today's U.S. health care delivery system and include the patient's sociocultural and family context in their patient interactions. Physicians should embrace the participatory decision-making model and support the patient's autonomy. Doctors need to be sensitive to the patient's clues and unvoiced desires. When a medical error occurs, there should be prompt disclosure, a heartfelt apology, and fair compensation so that the integrity of the relationship is not derailed by the patient's feeling a need to resort to malpractice litigation. Physicians must be empathic and gain their patient's trust. The key to a good patient-physician relationship was espoused perhaps most simply by Professor Francis Weld Peabody of Harvard Medical School—"the secret of the care of the patient is in the caring for the patient" [21].

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CLINICAL PEARL

Type 2 Diabetes: Lifestyle Changes and Drug Treatment

Natalie A. Brooks, PharmD

More than 23 million individuals in the United States have diabetes—a figure that creates great urgency for finding the most effective and safest methods for treatment. Data show that therapies that lower hyperglycemia to the normoglycemic range can reduce morbidity, cardiovascular mortality, and microvascular complications in type 1 diabetes [1-3]. Likewise, intensive treatment strategies for type 2 diabetes have demonstrated a reduction in microvascular disease, but more recent data show no reduction in macrovascular disease [4-7]. Due to the potential for complications, initial treatment for decreasing hyperglycemia should be patient-specific and adjusted to achieve the American Diabetes Association (ADA) target A1c level of less than 7 percent [8]. While oral and injectable pharmacotherapies and insulin are often needed to maintain this level, the importance and benefit of lifestyle changes should not be undervalued. According to the 2008 consensus statement from the ADA and European Association for the Study of Diabetes, lifestyle interventions and metformin therapy should be started concurrently upon diagnosis of type 2 diabetes [9].

Macrovascular Disease Reduction

In selecting treatment for chronic disease, the mechanism of the disease should be considered. Obesity and a sedentary lifestyle, for example, contribute to the risk for and development of type 2 diabetes. Obesity is also a factor in insulin resistance, which is a major cause of elevated glucose levels. Weight reduction and an increase in physical activity improve glycemic control by reducing insulin resistance and lowering fasting blood glucose. Weight loss also lowers risk of cardiovascular disease by reducing hypertension and serum markers of inflammation and improving the lipid profile. One study noted that intentional weight loss, such as with bariatric surgery, reduced mortality [10]. Likewise, the Diabetes Prevention Program showed a 58 percent decrease in the incidence of type 2 diabetes among patients with impaired glucose tolerance who achieved at least a 7 percent weight loss over 2.8 years [11].

Diabetes treatments in general reduce hepatic glucose output, enhance insulin secretion, improve insulin sensitivity, and prolong the effects of glucagon-like peptide-1 (*GLP-1*). Despite these mechanisms and their abilities to lower blood glucose, pharmacotherapies for diabetes have shown varying effects on macrovascular disease outcomes. Metformin monotherapy reduced mortality from all causes by 26 percent compared to other conventional therapies in the 1998 UK Prospective Diabetes Study 34, while the controversial yet classic University Group Diabetes Program suggested that sulfonylureas may increase cardiovascular disease

mortality [5, 12]. Thiazolidinediones have mixed data, with meta-analyses showing a 30 to 40 percent increase in the risk for myocardial infarction with rosiglitazone [13]. Conversely, a 16 percent reduction in death, myocardial infarction, and stroke was seen in patients treated with pioglitazone in the PROactive trial [14]. Intensive insulin treatment given to critically ill patients in an intensive care unit reduced mortality by 42 percent compared to the conventional-treatment group [15]. No published clinical trials have examined the effects of exenatide, pramlintide, and sitagliptin on cardiovascular outcomes.

Tolerability and Contraindications

Side effects and contraindications figure importantly in selection of individualized treatment. In general, few side effects are associated with lifestyle modifications. Exercising may result in myalgias, and dietary changes may cause gastrointestinal symptoms. Patients with arthritis or neuropathies should follow strict physician recommendations to avoid injury. While there is no consensus on which type of diet is most appropriate for patients with type 2 diabetes, most clinicians agree that a plan that results in gradual and sustained weight loss provides the most benefit. Patients should learn from a registered dietitian or other health care professional how to develop a plan that is balanced and safe. Common side effects of medications used to treat type 2 diabetes include hypoglycemia, gastrointestinal discomfort, weight gain, and fluid retention. Some medications are contraindicated in patients with renal or liver impairment or congestive heart failure, which limits their use.

Sustaining Glycemic Control

One of the most important topics a patient and his or her physician should discuss prior to selecting therapy is the potential for sustaining the desired result. Patients often have difficulty introducing new dietary and exercise regimens into their daily routines due to time constraints or other logistical factors. Svetkey et al. studied patients who had lost at least 8 pounds during a 6-month weight-loss program to determine which of several factors—monthly personal contact, unlimited interactive technology, or self-directed control—produced the most sustainable weight loss over a 30-month period [16]. While personal contact and interactive technology were superior to self-control, 71 percent of all patients remained at or below their trial entry weight at the end of the trial.

The international multicenter study, A Diabetes Outcome Progression Trial (ADOPT), evaluated the glycemic-lowering sustainability of monotherapy with maximum doses of metformin, rosiglitazone, and glyburide in patients newly diagnosed with type 2 diabetes [17]. At 5 years, rosiglitazone significantly reduced the risk of monotherapy failure—defined as fasting blood glucose levels greater than 180 mg/dl—by 32 percent when compared with metformin, and by 63 percent when compared with glyburide. A 2008 trial reported that intensive insulin therapy in newly diagnosed patients sustained the acute insulin response at 1 year compared to oral hypoglycemic agents, suggesting preservation of B-cell function [18]. Of course, adherence to the therapies is necessary to realize the benefits. As with other chronic disease states that require medication, adherence is influenced by patient perceptions

of the benefits of treatment and their understanding of the regimen, the complexity of the regimen, and patients' emotional well-being. Adherence rates to oral diabetes medications range from 65 to 85 percent and for insulin, from 60 to 80 percent [19].

Cost

Because lifestyle modifications and medications are usually recommended throughout life to maintain adequate glycemic control, the cost-effectiveness of each therapy should be taken into consideration. A subgroup of the Diabetes Prevention Program Research Group performed a within-trial, cost-effectiveness analysis comparing lifestyle intervention—defined as achieving and maintaining a 7 percent weight loss—with metformin (850 mg twice daily) [20]. Costs were based on the way the interventions would be implemented into routine, clinical practice and also from a societal perspective that considered direct medical cost, direct nonmedical cost, and indirect cost. In the 2003 report on the study, lifestyle intervention cost \$13,200 and metformin cost \$14,300 to prevent or delay one case of diabetes over 3 years.

When selecting the most appropriate therapy for treatment, the percent reduction needed to achieve the A1c target should be taken into account. The A1c-lowering potential for available therapies are listed in Table 1 [21]. When A1c levels are above 8.5 percent, combination therapies may be needed. If lifestyle modifications or the initial medications fail to achieve glycemic control in 2 to 3 months, additional therapy should be initiated. Fifty percent of patients initially controlled with monotherapy required a second agent after 3 years, and 75 percent needed multiple therapies by 9 years to achieve the target A1c [22]. It is agreed that initial treatment for patients with type 2 diabetes should include education on lifestyle modifications, diet, exercise, and setting reasonable goals to achieve a 5 to 10 percent initial weight loss. Regardless of the initial response to therapy, glycemic control and health behaviors should be continually evaluated to manage hyperglycemia most effectively. Therapies should be patient-specific and selected based on the potential for microvascular and macrovascular disease reduction, tolerability, sustainability, and expense.

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HEALTH LAW

Difficult Patient-Physician Relationships and the Risk of Medical Malpractice Litigation

Kristin E. Schleiter, JD

The patient-physician relationship is the cornerstone of the medical profession. Encounters between patients and their physicians are based on trust and give rise to physicians' ethical obligations to place patients' welfare above their own [1]. Successful medical care requires ongoing collaboration between patients and physicians, a partnership in which both members take an active role in the healing process [2, 3].

A sound patient-physician relationship enhances trust and encourages continuity of care, both of which contribute to patient health and well-being. A weak relationship, on the other hand, can affect patient care negatively and has been shown to put a physician at higher risk of being sued for medical malpractice [4-7]. A physician's exposure to medical malpractice litigation correlates, in turn, with lower levels of job satisfaction and diminishing emotional well-being. A physician who works through or ends a difficult patient-physician relationship must do so carefully to avoid litigation for patient abandonment and ensure that the patient preserves continuity of care.

Exposure to Medical Malpractice Litigation

The current malpractice environment is fueled less by quality failures than by failure of the patient-physician relationship, particularly in effective communication [4]. The impact of poor communication skills increases the likelihood that patients with adverse outcomes will sue, whether or not an error has occurred [8]. As Gerald Hickson noted, "risk is predicted by the practitioner's inability to communicate effectively and establish and maintain rapport with patients, especially in the face of an adverse event" [8]. In discussing the patient-physician relationship and its complications for malpractice litigation, Roter quotes Verghese:

Patients who like their doctors don't sue, no matter what their lawyer says. Our efforts in medical schools to turn out skilled yet empathetic physicians who communicate clearly and who can put themselves in their patients' shoes is [sic] critical to stemming the medical malpractice crisis. Patients sue when their feelings are ignored or when they are angered by lack of genuine concern for their welfare... Though it provides no guarantee, a sound physician-patient relationship is a powerful antidote to frivolous lawsuits [4].

Increasingly, doctors view patients as potential adversaries. One study reported that concerns about malpractice liability caused three-fourths of 824 specialists surveyed to view every patient as a potential litigant [9]. Moreover, physicians who had been sued and adopted the potential-litigant view of patients were more likely to practice defensive medicine, which further eroded their relationships with patients, regardless of the quality of clinical care. In this light, it is not surprising that a single malpractice lawsuit substantially increases the likelihood of future litigation [10]. Studies have shown that the practice styles of physicians who have and have not been sued do not typically differ in technical aspects of clinical care [10]. Rather, almost one-third of litigated complaints relate in some way to communication, such as inattentiveness, discourtesy and rudeness, a general breakdown in communication, and inadequate information [10].

Obstetrician Study. A study of sued and non-sued obstetricians found that patients who saw obstetricians with the most frequent number of prior lawsuits were significantly more likely to report spending less than 10 minutes with their physician during each visit; these individuals felt rushed or ignored, reported inadequate explanations for tests, and were more critical of the care they received [5, 10]. Researchers concluded that difficulty in communicating effectively increased vulnerability to lawsuits [5].

Satisfaction with Care Study. In another study, the degree of satisfaction a patient experienced with his or her physician was highly correlated with malpractice litigation [5, 6]. Not surprisingly, patients of physicians who had never been sued were the most satisfied [5, 6]. They were more likely to see their physicians as concerned, accessible, and willing to communicate [5, 6]. The most common complaints from patients whose physician had been sued were that physicians did not listen and physicians did not offer information [5]. Patients seen by physicians with a high frequency of litigation were most likely to be critical of the human aspects of care, such as interpersonal skills and communication [5, 6].

Litigation Studies. A study that examined deposition transcripts from malpractice litigation involving obstetrical care demonstrated that four types of communication problems were present in more than 70 percent of the depositions: (1) deserting the patient, (2) devaluing the patients' views, (3) delivering information poorly, and (4) failing to understand patients' perspectives [5, 7]. A similar study conducted interviews with unsolicited callers to law firms concerning medical malpractice complaints [11]. Researchers found that many factors affected patients' decisions to call, including poor relationships with providers before an injury (53 percent), television advertising by law firms (73 percent), and explicit recommendations by health care providers to seek legal counsel (27 percent) [11].

Both the litigation and the "satisfaction with care" studies showed that there was little or no objective evidence of malpractice in the cases reviewed, yet physicians were still sued [5]. Given that the primary sources of dissatisfaction had little to do

with clinical management, practitioners can reduce risk of litigation without a significant change in clinical practice [6].

Termination of the Patient-Physician Relationship

A patient-physician relationship may become so difficult that a physician deems it necessary to end the relationship—perhaps because the patient consistently refuses to follow orders, does not pay for services, or communication failures discussed above have caused the irreparable breakdown of the relationship. When this occurs, the physician must take steps to ensure continuity of care for the patient and avoid a legal action for abandonment.

There are some exceptions, however. A physician cannot be liable for abandonment if no treatment relationship existed between the parties during the course of the patient's illness. A specialist, for example, who has seen a patient for one illness is generally not obligated to continue to treat the patient once the treatment for that illness is completed [12]. Similarly, a physician who refers a patient to a specialist and tells him or her that the specialist is thereafter assuming the primary responsibility for the case has not abandoned the patient by refusing to accept responsibility for further care [12]. Finally, a physician has the right to limit his or her relationship with a patient so long as the limitations are made clear at the onset of the relationship [12].

A patient may terminate the patient-physician relationship at any time. In this case, a physician has a duty to warn the patient of his or her need to obtain further medical care. If the condition requires further medical care, the physician must provide the patient's succeeding physician with enough information to ensure continuity of medical treatment [12]. A prudent physician will send the patient a letter by registered mail confirming that he or she has been discharged and stating the need for continuing treatment [12].

A physician is also free to terminate the relationship, even without providing a specific reason for withdrawal. When doing so, the physician must give the patient sufficient time to find another physician or make some other arrangement for the provision of necessary medical services.

Given the rate of litigation stemming from poor communication and other nonclinical relationship failures, improving relationship skills is worth the effort. If a patient-physician relationship has deteriorated to the point where the physician feels it is necessary to terminate it, taking a few steps will ensure that effective communication, continuity of care, and the physician's emotional and professional well-being are protected.

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POLICY FORUM

Responsibility and Collaboration in Health Team Care

Kelly Dineen, RN, JD

During one unusually quiet night in the ICU, I delegated a blood draw to a patient-care assistant believing she would perform a venipuncture for routine lab work [1]. An hour or so later, I walked in the room and discovered she had unilaterally decided to stop an infusion and draw blood from the patient's central line, she was preparing to flush the line. The assistant was well aware that accessing the central line was outside the parameters of her delegated nursing duties. I had trusted her (as a professional and with my license) to adhere to those parameters.

I suspect this otherwise benign story sticks with me years later because of the assistant's arbitrary violation of trust and lack of respect for professional boundaries. What is reassuring and surprising, however, is that, after 10 years in practice, this is my only memory of a professional at any level having deliberately stepped over his or her respective scope of practice. Obtaining blood for labs is among the most routine of tasks in health care; yet, even the most routine acts are undertaken in a chain of supervision, delegation, and cooperation ranging from the attending physician to the laboratory technician.

A violation of trust may, at best, undermine otherwise effective practice patterns and, at worst, threaten a patient's life. Adherence to the few existing bright lines in the murky world of professional caregiver roles is essential to the foundation of collaborative patient care. The shared knowledge that those lines will not be crossed and mutual trust among professionals are what justify the gentle push on the margins that occurs when nonphysicians exercise judgment and autonomy at the highest permissible level. This can make all the difference for the patient. It is, for example, what allows an ICU nurse caring for an unstable patient to anticipate the physician's orders in those precious moments between the page and returned call. It enables surgeons to leave their post-op patients in the hands of others while they are in surgery. It underscores quality health care from a carefully choreographed code response to effective preventive care.

In the new model of comprehensive patient care, physicians alone cannot meet the full range of the patients' medical and health-promotion needs. Effective patient care, from the routine to the most sophisticated, depends heavily upon a delicate combination of individual responsibility and collective trust. It often relies upon an intricate system of professional supervision, delegation, and collaboration among caregivers from many disciplines and levels of education, training, licensure, and independence. The role and scope of practice is affected by a host of factors that include state licensure laws, federal and state regulations, institutional policies, and

contractual obligations. And the precise role of any group or individual can be further dependent upon place and circumstance. Hence, each professional is responsible for understanding his or her own and other professionals' scope of practice. For nearly a decade, organizations such as the Institute of Medicine, the American Medical Association, and the American Osteopathic Association have recognized the need for the effective and efficient use of interdisciplinary teams in the delivery of health care [2].

Physicians, more than any other group, must balance the benefits of collaboration with the responsibility for health care delivered by nonphysician health team members. Highly trained nonphysician caregivers—primarily physician assistants (PAs) and advanced practice registered nurses (APRNs)—are increasingly utilized to complement and supplement medical care. PAs and APRNs are distinct disciplines in training and practice but are sometimes collectively referred to as physician extenders, a term that reflects the financial realities and regulatory mandates that have created physician coverage shortages for which PAs and APRNs are often considered a partial solution [3]. Nonetheless, the term physician extenders misrepresents, oversimplifies, and diminishes the role of the PA and APRN in patient care and the relationship between the physician and the PA or APRN.

The balance of shared and individual responsibility and trust between physicians and PAs or APRNs is among the most complicated and beneficial relationships in health care delivery. New physicians undoubtedly need guidance to negotiate the roles and duties attendant upon working with these professionals. Even for those physicians who generally understand the work of PAs and APRNs, specific information regarding an individual's scope of practice is dependent upon multiple factors. Because of the differences in state regulation, training, and individual agreements among PAs or APRNs, institutions, and physicians, the scope of practice varies from individual to individual. Depending upon the circumstances, PAs and APRNs may be practicing independently or subsequent to physician delegation, and each of these has associated consequences for the PA or APRN and the physician. Therefore, collaborating professionals must assume responsibility for communicating and understanding their respective roles and for practicing within these parameters.

Physician Assistants

“Physician assistants seek and embrace a physician-delegated scope of practice. This is unique. No other health profession sees itself as entirely complementary to the care provided by physicians” [4]. PAs practice medicine subject to physician delegation and supervision. Their duties may include diagnosing and treating illness, performing or assisting with procedures and surgery, ordering and interpreting tests, and prescribing medication. Within the boundaries of the physician-PA relationship, PAs make autonomous medical decisions [4].

PA education is based on the medical model. The curriculum is generalist in nature with a focus on primary care, although many PAs subsequently specialize in practice [4]. PA programs are typically graduate programs of just over 2 years of full-time

study and are accredited by the Accreditation Review Commission on Education for the Physician Assistant [5]. At the completion of their studies, PAs take the Physician Assistant National Certifying Examination and must maintain their certification by completing mandatory continuing medical educational courses each year and passing a recertification exam every 6 years [6]. All PAs except those who work for the federal government and are credentialed under a separate process must obtain state licensure to practice. In all 50 states, eligibility for initial state licensure is dependent upon certification [7].

The PA's scope of practice is defined, in part, by state licensing laws and agency rules. Some states allow supervising physicians the discretion to determine appropriate delegation of medical care to the PA while some states literally list tasks and procedures that PAs may perform. There are also significant variations in the definition of supervision, the number of PAs a physician may supervise, and prescriptive authority granted to PAs [8].

Delegation or supervision agreements between the physician and the PA also impact the PA's scope of practice [9]. Institutions often require submission of the agreement to grant a PA privileges. Some state licensing boards require that PA-physician agreements be submitted for approval or rejection by the board [10]. Physicians who fail to adhere to supervision agreements with PAs risk professional discipline from the state medical board [11]. It is therefore imperative that supervising physicians and PAs adhere to the parameters set forth in these agreements and clearly communicate those limits to those with whom they work.

Advanced Practice Registered Nurses

APRNs are registered nurses with "advanced education, knowledge, skills and scopes of practice. Most APRNs possess a master's or doctoral degree in nursing" [12]. APRNs practice in one of four primary roles: (1) nurse practitioner, (2) clinical nurse specialist, (3) nurse midwife, or (4) certified registered nurse anesthetist [13].

The minimum level of graduate education for an APRN is a master's degree, and several groups have endorsed the doctoral level as the entry level for nurse practitioners. The education for APRNs is designed to prepare practitioners to deliver care in one of the four primary roles directed at one or more demographic groups or "population foci" such as families, children (pediatrics), newborns (neonatology), and the elderly (gerontology) [14]. These populations are often the basis for credentialing exams that are frequently a prerequisite for licensure as an APRN. Thus, a medical student could encounter any number of APRNs in a hospital with drastically different skill sets, practice areas, certifications, licensure, and scopes of practice. To complicate matters further, APRNs often have collaborative practice agreements with physicians as well as contracts with hospital systems that further define their scope of practice.

Unlike PAs, APRNs' practice is considered distinct from the practice of medicine. Nursing education emphasizes a holistic approach to patient care across a continuum

of health states from wellness to serious illness. The promotion of health is of primary importance. While APRNs often treat patients with illnesses in much the same way as a PA or physician, the approach to assessment and care is distinct from the medical model. In fact, nursing leaders envision APRNs as independent practitioners without regulatory requirements for physician supervision or collaboration [14]. In practice, the level of independence is dictated by state licensure laws that define if and when collaboration and supervision are needed.

The oldest and perhaps most straightforward of the APRN roles are the midwife and the certified registered nurse anesthetist. Certified registered nurse anesthetists are recognized in all 50 states and are responsible for 65 percent of the anesthesia given to patients. They have well-defined graduate education and certification programs. Nurse midwives are highly autonomous, specialized, and recognized in 48 states.

In academic medicine, hospital systems, and private practice, nurse practitioners and clinical nurse specialists are used increasingly in patient care and, unlike certified registered nurse anesthetists and midwives, practice in a number of settings and specialties. Although the roles of nurse practitioners and clinical nurse specialists are prone to significant overlap, nurse practitioners tend to spend more time providing direct patient care than their clinical nurse specialist counterparts [12].

In 2008, several national organizations including the National Council of State Boards of Nursing and the American Nurses Association endorsed and published a consensus model for the regulation of APRNs [14]. The consensus statement envisions a uniform system of education, credentialing, and state regulation, as well as independent practice for APRNs.

Each APRN is accountable to patients, the nursing profession, and the licensing board to comply with the requirements of the state nurse practice act and the quality of advanced nursing care rendered; for recognizing limits of knowledge and experience, planning for the management of situations beyond the APRN's expertise; and for consulting with or referring patients to other health care providers as appropriate [14].

Liability Concerns for Physicians Working with PAs and APRNs

PAs and APRNs provide documented benefits in the areas of patient satisfaction, quality of care and resource allocation. A significant area of concern for physicians, however, is the potential for exposure to professional and licensure liability. Physicians may be held liable for the actions of a PA or APRN who acts within the boundaries of a supervision agreement or collaborative practice agreement. The determination of liability depends upon the level of supervision and the laws of the state of practice [15].

Independent practice for APRNs would potentially protect physicians from malpractice liability or licensure actions by shifting sole responsibility for practice to the APRN. On the other hand, the PA profession advances the PA as the agent of the

supervising physician in every aspect of the PA's practice [9]. As PAs and APRNs are increasingly prevalent and autonomous in health care, some commentators have urged a change in liability standards that allocate responsibility to PAs, APRNs, and physicians for the care provided [16].

Physicians may also face discipline by their state board of medicine for failing to comply with agreements or even for aiding and abetting the unlicensed practice of medicine [17]. In reality, most of these concerns are manageable by adhering to the agreements entered with the PA and APRN. Physicians who seek to employ, supervise, or collaborate with PAs or APRNs must also verify licensure and certification with the respective state licensing board before allowing the PA or APRN to practice.

For medical students and residents who work with but do not supervise or collaborate with PAs and APRNs, there are far fewer concerns about liability. Physicians cannot presume to know the boundaries of any one health professional's practice because state regulations, practice requirements, and agreements among the PA or APRN, physicians, and institutions are subject to change. Each member of the team is responsible for adhering to his or her scope of practice and communicating with one another about the respective roles in patient care.

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MEDICINE AND SOCIETY

New Forces Shaping the Patient-Physician Relationship

Howard A. Brody, MD, PhD

Dr. Burke, a primary care physician, is seeing Mrs. Carter during a return visit to evaluate a new medication and exercise regimen she has recommended for Mrs. Carter's osteoarthritis of the knee. Mrs. Carter is very pleased and mentions that she is now able to work in her garden again.

Dr. Burke uses a version of the electronic medical record (EMR) that facilitates narrative notes in addition to check-off options. She adds the comment, "Able to work in garden again," to her progress note for the visit.

On the next visit, Dr. Burke reviews her previous note and asks Mrs. Carter at the beginning of the session, "And how is your garden coming along?" Mrs. Carter is pleased that the doctor remembered her favorite hobby.

Dr. Gold, another primary care physician, has an identical encounter with his own osteoarthritis patient, Mrs. Carter. The form of EMR he uses makes it very complicated to add narrative notes and favors check-off boxes. He clicks on the box, "Joint function: improved."

During the next follow-up visit, Dr. Gold cannot remember whether it was Mrs. Carter or one of his other patients who liked to garden. He decides to play safe and not bring up the subject.

EMR's Impact

Most experts are enthusiastic about the potential of the EMR to improve quality of care and reduce costs. What impact will the EMR have on the patient-physician relationship? As the above hypothetical and anecdotal cases study suggest, that depends.

I am simplifying greatly in suggesting that there is such a thing as *the* patient-physician relationship that might be altered by new developments. Different models for the relationship have been proposed and debated [1]. For this discussion I am assuming that the "traditional" relationship has three important elements—first, the patient's awareness of the physician's fiduciary duty to serve the patient's health-related interests; second, the patient's sense of being treated as a unique person and not simply as a case of medical disease; and finally, an openness to active give-and-take, with patients participating in therapeutic decisions to the extent that they wish.

The EMR is only one of a series of innovations that promise to affect the patient-physician relationship in ways that may be without precedent. The field of bioethics has always shown a great interest in anticipating the ethical consequences of new medical technologies—from organ transplantation and mechanical ventilation, to stem cells and nanoparticles. The field has shown less proclivity for investigating new forms of personal and social relationships [2].

Bioethics' neglect of relationships may mirror its lack of interest in primary-care issues. Subspecialty practice often defines itself in terms of its technological tools. Primary-care practice defines itself in terms of the relationship, with the patient at its core. Thus, continuity of care and personalized care are definitive features of primary care.

It is past time to be exploring the impact recent innovations are likely to have on the relationship. One way of focusing the discussion is to look at the idea of the “medical home” and pay-for-performance (P4P).

The Medical Home

Developed in pediatrics as a model for caring for special-needs children, the medical-home concept has now been embraced in family medicine and general internal medicine and has caught the interest of health policy analysts [3]. The enthusiasm is driven by the realization that most patients suffer from one or more chronic illnesses, and the U.S. system does a poor job of managing those patients and their illnesses. The medical home promises a number of features that could help the system do a better job.

- Patient-centered care, such as same-day scheduling and ease of access by telephone, e-mail, and Internet.
- EMR and aggressive quality monitoring.
- Interdisciplinary team care.
- Coordination of care, whether delivered on-site or referred outside.
- Focus on prevention and health education, including group visits.

These components should not obscure the basic idea of the medical *home*. Home is a place in which we feel *welcomed*. If patients do not experience a welcoming environment when they arrive, the other features, however impressive, will not accomplish what is needed.

If the medical-home concept develops as now envisioned, patients will find themselves experiencing an ongoing personal relationship with, not one individual, but a facility and team of individuals. Because coordinated team care seems to offer so many advantages for dealing effectively with the demands of preventive medicine for chronic illnesses, we hope that this transition will be a net plus for the patient. Whether it will or not, and what the specific gains and losses might be, will require careful study and monitoring. We can readily imagine how transferring allegiance from a primary physician to a care team and clinic facility could lead to a diminished

sense of a personal relationship. There are, however, important opportunities for expanding the notion of relationship that also ought to be factored in and studied.

Consider the idea of group visits—a group of patients with diabetes meet monthly to discuss topics like diet, exercise, and foot care with the physician, nurse, or nutritionist. These patients supplement the relationship with their physicians and other team members with the interactions among a group of other patients suffering from the same condition. At group visit meetings, they share tips that each has learned about self-management of diabetes and provide mutual emotional support and encouragement. Social support of this kind can itself be a factor in improving health outcomes, along with advice and encouragement the patient receives regarding diabetes.

Finally, the ideal medical home will exist in a relationship with the community in addition to its individual relationships with patients. If the medical home follows the model of one of the most successful types of primary care facility—the federally qualified community health center—it will have a community advisory board to help ensure that the voice of community representatives is heard and the health needs of the community are understood, through the eyes of its members. The medical home that pursues this model will be a public health facility as well as an individual-care facility, responsive to its patients' needs at all levels.

In sum, the medical home threatens the traditional patient-physician relationship in some ways but also offers to deepen and expand it. What about another policy innovation—pay-for-performance (P4P)?

Pay-for-Performance

It has been difficult to find any policymaker willing to say anything bad about P4P because at first blush it sounds like the ideal solution to the age-old problem—how can I pay my physician when, *and only when*, he or she does something that benefits my health? The advent of so-called evidence-based practice guidelines holds out the promise that we can measure quality care precisely. If we then tie reimbursement to guideline adherence, perhaps we have finally reached the economic nirvana.

Sadly, the reality falls rather short of the ideal. The actual evidence regarding P4P, and the degree to which practice guidelines actually reflect the best available evidence, is rather discouraging [4].

It is relatively easy to measure the percentage of diabetic patients for whom the physician has ordered a glycohemoglobin level test in the last 12 months. It is much more difficult to measure the components of the patient-physician encounter that go toward creating and sustaining a personal relationship. In all such cases, the measurable usually drives out the important. When physicians are paid a lot for doing discrete, technical procedures and very little for spending time with and talking to patients, we have the sort of health system we have today, which is long on procedures and short on meaningful relationships.

Society values both the appropriate use of new technological and management innovations and the maintenance of a strong personal and therapeutic relationship between patients and physicians. My recommendations are to embrace the medical-home model but be wary of P4P [2]. In each case much more evidence will be required to determine real outcomes and discover whether either the promise or the peril has been realized in practice.

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MEDICAL NARRATIVE

Yes, We Do Give Frequent Flyer (S)Miles

Chris Brooks, MD

I can recall writing a note in Walter's chart like it was yesterday [1]. It began, "This is the 200th emergency department visit for Walter this year," and it was only mid-summer. Less than 6 months later accounts of this infamous patient's last days circulated though the hospital. In a strange way, I felt as though a family member had died.

Walter had been a fixture in our department for many years. Every physician in the emergency department knew him well, as did many of the internal medicine physicians. Nurses and technicians were on a first-name basis with Walter, who was renowned not only in our department but in most emergency departments in the city.

Encounters with Walter were always difficult at best. He would wander in at random times with vague or chronic complaints. With his head down, he would shuffle into the waiting room mumbling complaints in a monotone, high-pitched voice to the triage nurse. Refusal to cooperate with care was his custom. He would be found sitting in his assigned room, nearly every square inch of his body covered with ragged, unwashed clothing. A sweatshirt hood (or two) often covered his head. Taking of vital signs was usually refused, as was most diagnostic testing. House staff were often surprised to learn that Walter was neither uneducated nor homeless. In fact, he held an advanced engineering degree and, despite roaming the hospital campus at all hours of the day, owned his own home.

In spite of his usual vague and chronic complaints, Walter had advanced congestive heart failure. He was one of those patients always ill enough to be admitted to the hospital, even on his best days. He had chronic hypoxia, severe edema of his lower extremities, and chronic renal insufficiency. Discussions about administering furosemide were usually met with arguments by Walter about how it would affect his renal function coupled with refusal of a lab test for a serum creatinine. Walter firmly resisted any suggestion for hospital admission but was often so ill that he lacked the energy to refuse. These times offered a respite for the emergency department. It was easy to tell when Walter was in the hospital; those were the days when he wasn't in our emergency department.

The crux of the matter was Walter's underlying paranoid schizophrenia, which he refused to acknowledge. In fact, the one sure way to get him to leave the emergency department was to threaten to consult psychiatry. Mere mention of the service would result in cries of anguish, and his elopement from the department would soon follow. Surprisingly, this strategy was seldom used. Perhaps the staff realized that efforts to

address his underlying psychiatric illness would be futile. Walter was never a threat to others or to himself, except for his medical noncompliance.

Descriptions circulating through the hospital surrounding the circumstances of Walter's death were troubling. He had been admitted for worsening dyspnea and, as usual, had refused most interventions. His status declined, prompting his transfer to the intensive care unit where psychiatry was consulted. Numerous therapeutic modalities were then imposed, but Walter's condition continued to worsen, and he eventually succumbed to his illness. One can only imagine the anguish resulting from his loss of autonomy during his final days.

Discussion

Patients who are regulars in emergency departments have been given many titles including "frequent flyers." The "problem" is not unique to the United States. English-language literature describing the characteristics of these patients and the issues surrounding their emergency department care comes from many countries [2-9]. The implication is usually that patients are somehow using the emergency department in an inappropriate manner. Studies have clearly shown, however, that about half have chronic medical conditions, and for a variety of reasons most are not able to be seen in the offices of primary care physicians [2, 4-6, 8, 10-12]. Furthermore, these patients comprise a complex group that is in constant flux. The majority frequent the emergency department for a short period of time, usually less than 1 year, but there is a small minority that visits the emergency department over a long period of time, often many years [11]. This subgroup is studied little but is often the source of emergency department lore [13].

Walter is one of the few who maintained his familiarity with the emergency department staff over time. Like many patients in this subgroup, he was labeled "difficult," a label that is fraught with problems. Descriptions and categorizations of so-called difficult patients have been in existence for many years, the modern classic being Groves's article, "Taking Care of the Hateful Patient" [14]. The term is used to indicate that such patients are noncompliant, manipulative, and self-destructive. Differing expectations on the part of patient and physician can produce mutually negative outcomes in the medical encounter. Two traditional physician views present barriers to an ideal patient-physician relationship: the concept itself of the difficult patient and a biomedical view of medicine that tends to exclude social conditions. Patients like Walter are perceived by medical caregivers as "at fault" for poor medical outcomes. In many of these cases, unaddressed psychosocial issues are the root of the patients' repeat visits, but attempts to manage those issues don't necessarily reduce the number of emergency department encounters [15]. Phillips et al., for example, found that case-management strategies increase emergency department utilization, even while having a positive effect on some psychosocial factors for frequent users [3].

There are common factors among the frequent user group. Those with poor health, low income, psychiatric illness, substance misuse, and public insurance are more

likely to be frequent users [8, 12, 16, 17]. Health insurance seems to otherwise not matter, nor does access to care [18].

Few studies have examined the underlying reasons that patients frequent the emergency department. Examining the issue from the patient's perspective, Olsson and Hansagi found that frequent emergency department visitors perceive pain or other symptoms as a threat to their life or personal autonomy [9]. Overwhelming anxiety compels them to seek urgent help. Satisfaction with care becomes adversely affected when the patients sense that the emergency department staff classifies their frequent visits as inappropriate or when their symptoms are belittled.

In our case, Walter developed long-term relationships with various members of our emergency department staff. Many suspected that, like the ultimate frequent flyer, Walter had a social, albeit dysfunctional, relationship with them [13]. It is interesting that resources tend to be used in a more efficient manner on the long-term subgroup of frequent users than on the short-term group. Perhaps emergency department providers streamline the evaluation process due to familiarity with the patient, or they come to terms with the conflicting goals of therapy that are so troubling in encounters with difficult patients. My last few encounters with Walter were cordial and, in fact, quite rewarding. Accepting the limitations on care imposed by the patient, being willing to deviate from what most physicians would label "standard of care," and patience were universally rewarded. Here, respect for patient autonomy was all that was demanded and took priority over other values. Not all of our colleagues agreed with this approach, but expanding care to include psychosocial as well as medical needs led to a rewarding patient-physician relationship.

Many do not consider the emergency department to be a place where long-term relationships are typically built. Cases like Walter's, however, illustrate that the potential for them exists here. Emergency department physicians do, on occasion, form deep, meaningful relationships with their patients. Today, other patients have taken Walter's place in our department. Some of them are quite objectionable, but all seem to have unique psychosocial needs that present an almost daily challenge. Meeting these needs and improving their lives continues to be a rewarding experience.

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SUGGESTED READINGS AND RESOURCES

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