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Break point

JOSEPH H. FRIEDMAN, MD
joseph_friedman@brown.edu

ALL CLINICIANS HAVE anxious patients since anxiety is a common problem, and illnesses both breed and amplify anxiety. In a clever study published by a New York City movement disorders specialist, it was found that the bulk of patient calls from people with Parkinson's Disease (PD)



were made by patients who suffered from anxiety. This not only made sense, but also rang true. I know that I experience a lot more trepidation when I'm calling back my patient who has called three times in the past week with complaints of feeling jittery, medications not working quite right, a bad night's sleep or a variety of other problems. This differs from the calls from the patients who report major problems, a sudden decline, a "should I go to the emergency room" call, or, "he's calling the police about the people in the living room who won't leave." But I've noticed a pattern in some callers and it brings to the surface my own worries about my weaknesses as a doctor.

It took me many years of clinical practice to realize that the major benefits I bring to my patients are stability and comfort. Yes, I'm a presumed expert. I give invited talks. I consult for industry and am considered a "key opinion leader" (KOL) in the pharmaceutical world, which either means I write a lot

of prescriptions or am a recognized expert, depending on the company. I publish papers. I may or may not be a skilled technocrat, but, whether yes or no, assuming I'm at least competent, it became clear to me that the role of most significance I play is the long-term pastoral role.

I've written of this before in this column, but I'm revisiting the topic because of an insight. I have known for many years that certain patients will

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suddenly start calling a lot, and they will do this for weeks to months, several times each week, with the "usual" complaints we hear in PD: I'm falling; I'm having too many movements (dyskinesia); I have more "off" time; my speech is terrible; I'm hallucinating; I'm fatigued all the time; I can't sleep. These are difficult for me, partly, of course, because the calls take time and, at the end of the day, or lunchtime, there are other things I need to do. But, primarily, they are difficult because these patients are usually calling because they are failing. I know this. Their illness has advanced and they

are becoming disabled to a point they can not tolerate and won't accept.

It takes time to accommodate. While the "degenerative" neurological diseases like PD and Alzheimer's progress at a fairly stable rate, the functional disabilities do not. I often invoke the analogy of the hurdler who, with declining abilities, clears the hurdles by less and less, a decline noted by the coach. The hurdler, however, experiences a different reality. One day he clears the hurdle and the next he hits it. A slow, continuous decline physiologically translates to a sudden step-wise fall-off in function. The degenerative disorders are similar.

A small decline in cognition may lead to a major change in independence. A small change in the number of dopamine receptors may spell a dramatic change in dyskinesias or the severity of a freezing gait.

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I am helpless. I make changes. I raise

this, lower that, alter the schedule, all the while thinking to myself, how long will it take for the patient to realize that this terrible, intolerable situation is going to have to become tolerable, that there is no escape.

Recently the spouse of a patient, who, along with the patient, had been calling frequently, one right after the other, so that I had two calls a day, finally asked, “Is this the way it’s going to be? I see people at the support groups and none look like my wife. She looks worse than others who have had the disease for 10 years, and she’s had it only three. Is there something different about her condition? Please tell me. Is there anything that can be done?” Once we addressed this issue., “Yes, this disease is worse than the “usual.” It probably isn’t PD but one of the mimics, which is worse. We’ve been very aggressive about the

treatments. We can’t do more. I’m sorry, but I’ve tried everything.” And that cleared it up. They understood. This was the new normal. She was different than the others. I had nothing up my sleeve. No more calls.

I have thought about this a long while and have not decided whether it’s better to let patients and family reach this state on their own, or whether I should step in early and say, “This is what’s going on. Scale down your expectations. We’ll do what we can but there are no miracles, even small ones, here.” “So, you’re telling me to ‘suck it up,’ aren’t you? There’s nothing that can be done,” is the response I dread. It has happened. I have done this and it’s like telling someone they’re going to die. It’s difficult no matter how gently I am able to phrase it. Tough love or compassionate realism? In the meanwhile, I answer all my phone

calls, and try, as best I can, to be compassionate. It is not always easy when answering the fifth call from the same patient. But sometimes this is enough. It always stops, but often because they’ve reached rock bottom. No hope left. Accommodation or surrender? Either way, it makes my life easier and that is the source of my guilt. ❖

Author

Joseph H. Friedman, MD, is Editor-in-chief of the *Rhode Island Medical Journal*, Professor and the Chief of the Division of Movement Disorders, Department of Neurology at the Alpert Medical School of Brown University, chief of Butler Hospital’s Movement Disorders Program and first recipient of the Stanley Aronson Chair in Neurodegenerative Disorders.

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Ethical decision-making and patients' beliefs

HERBERT RAKATANSKY, MD

AT A RECENT LECTURE by a noted ethicist (also a physician) about sensitivity to patient's values and beliefs, the statement was made that the doctor never should do any thing that s/he thought was wrong.

Rare though they may be, there are situations in which the statement made by the ethicist does

not seem to apply. The problem arises when strongly held beliefs of the doctor conflict with an appropriate medical therapy desired by the patient.

The validity of the admonition of the ethicist to never do anything wrong depends on the definition of wrong. If the doctor has a belief system different from the patient there is a clash of values resulting in differing opinions about the "wrongness" of certain treatment plans.

Autonomy dictates that a competent adult patient may reject any medical treatment, even if such a decision results in harm or death. For example, a patient may refuse blood products, based on the tenets of a religious belief.

But should a doctor who is an observant Jehovah's Witness (JW) decline to order blood transfusions for a bleeding patient who wants them? Online discussions seem to imply that a JW doctor should refer such treatment to another physician. But what if no other qualified physician was available? There is also discussion of the difference between



making the decision to use blood and the actual administration of the blood by a JW professional who is just following the order. Making the decision to give blood seems to be the critical issue to some. Personally I have not encountered or been aware of a JW doctor in any situation.

The problem with the imperative not to do something one knows is "wrong" may appear in a different context. What if a doctor is asked to treat a JW patient who refuses blood products when they may be an essential part of the treatment? The doctor may construe that "partial"

treatment is wrong. Guidelines for anesthesiologists in the UK¹ address this issue:

"Anaesthetists have the right to refuse to anaesthetise an individual in an elective situation but should attempt to refer the case to a suitably qualified colleague prepared to undertake it...In an emergency, the anaesthetist is obliged to provide care and *must* respect the patient's competently expressed views."

Other consequences may contribute to a doctor's opinion that partial treatment is wrong.

"Working within restrictions imposed by Jehovah's Witness patients can result in diversion of hospital resources from

other patients who have a medically indicated need for them." This "may result in a lack of resources being available to other patients. The ripple effect on other members of the theatre teams and ward staff may also be profound. Counseling may be required for the... team who may feel that, whilst adhering to the patient's expressed wishes, they have been unable to provide an optimal level of care that has resulted in a significant morbidity or even death during their care."

In another case, the prohibition of termination of a nonviable fetus for any reason (hospital policy) created the

More commonly, patients may make end-of-life decisions based on values that differ from those of the doctor. What is the doctor to do in these situations?

situation in which an ER doctor in Muskegon, MI, refused treatment to a woman 18 weeks pregnant whose waters broke and presented with excruciating pain. Definitive treatment was delayed for over 24 hours because of this restriction. Referral was not offered (it is not clear if it was available) and she was finally treated only when she began to have a spontaneous miscarriage. The personal belief system of the doctor(s) was not noted in the report of this incident.

More commonly, patients may make end-of-life decisions based on values that differ from those of the doctor. What is the doctor to do in these situations?

When a doctor's beliefs impel him to act contrary to the stated wishes of the patient for appropriate medical treatment, the doctor should refer the patient to other doctors or institutions that provide that treatment. But what if there are no other resources available and there is an emergency situation?

The 8th of the 9 principles of medical ethics that define the basic values underlying the entire AMA code of ethics puts the patient first, which is where I like to be when I am the patient. This basic imperative has an overarching reach: "VIII. A physician shall, while caring for a patient, regard responsibility to the a patient as paramount."

In accordance with this principle. Opinion 10.06 of the AMA code states in part: "Physicians' freedom to act according to conscience is not unlimited, however. Physicians are expected to provide care in emergencies, honor patients' informed decisions to refuse life-sustaining treatment, and respect basic civil liberties and not discriminate against individuals in deciding whether to enter into a professional relationship with a new patient."

Physicians should "inform the patient about all relevant options for treatment, including options to which the physician morally objects..."

Physicians should be aware of this basic moral obligation and strive to avoid putting themselves into situations where this conflict may arise.

It may be difficult to figure out what to advise our patients in a specific situation and we may get it wrong. Being wrong may be the result of many factors including, but not limited to, lack of information, poor judgment, lack of proficiency and others, but should not be the result of a conscious decision due to personal beliefs to act against the best interests of the patient, as defined by the patient. Our patients must trust that we will always be their advocates.

Medical students should understand this value so that they may choose wisely from the many options in medicine.

I interpret the ethicist's statement as meaning that it is wrong to act in a manner contrary to the self-defined best interest of the patient. In this context I conclude he was correct. ❖

Reference

1. Management of Anaesthesia for Jehovah's Witnesses, 2nd edition, Nov. 2005 Association of Anaesthetists of Great Britain and Ireland

Author

Herbert Rakatansky, MD, is Clinical Professor of Medicine Emeritus, The Warren Alpert Medical School of Brown University.