Autonomy and the “demanding encounter” in clinical neurology

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Summary

We describe a case of psychogenic nonepileptic seizures as an example of what has been called the demanding encounter in clinical neurology. Patients in these encounters are more likely to see themselves as informed consumers who expect to receive requested diagnostic tests and treatments from health care providers, potentially creating a conflict over treatment goals and appropriate limit setting. Demanding encounters are associated with physician burnout and patient dissatisfaction. We survey some of the ethical frameworks introduced to navigate this type of encounter. We argue that physicians are obligated to identify the underlying beliefs that are leading to requests for unnecessary testing and treatment and that, by addressing these beliefs, providers have the best chance of establishing a respectful, meaningful therapeutic relationship with their patients.

Susan, a fictional patient, is a 35-year-old woman with a history of depression who is referred to the neurology clinic for 1 year of shaking episodes. These episodes start with a tingling sensation in both legs followed by generalized weakness. Witnesses report that she has nonrhythmic shrugging of her shoulders without jerking her arms or legs. She never loses bowel or bladder control and has never been injured because of these episodes. Afterward, witnesses report that she is fully conversant, oriented, and can describe what happened. She does not, however, feel back to her usual self for several hours. She does not have any family history of neurologic disease or premorbid risk factors for epilepsy. She denies history of abuse, psychosocial trauma, alcohol abuse, or illicit drug use. She feels that she has had no recent stressful events. She denies any significant marital strife with her husband of several years.

The first time Susan experienced an event she was taken to the hospital. Extensive evaluation, including head imaging, was unremarkable. EEG with video was performed for 24 hours

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and captured one of her episodes, which had no electrographic evidence of seizure. On the basis of these tests, she was told that these were likely stress-related events.

Because Susan continued to have these episodes, she was readmitted to the hospital and underwent continuous video EEG monitoring for 5 days. Several episodes were captured and once again there was no evidence of electrographic seizures. She was diagnosed with psychogenic nonepileptic seizures (PNES) and referred to a psychologist to assist with cognitive behavioral therapy and stress management training. Unsatisfied, she self-referred to an epilepsy specialist, who also diagnosed her with PNES. She began to have the episodes with increased frequency and she started to miss work and to limit her interactions with friends and family. Given her degree of impairment, she was once again admitted to the hospital for extended EEG monitoring. There was again no electrographic correlate to her shaking episodes.

Susan has self-referred to a third neurologist for another opinion. She feels she might have an undiagnosed brain tumor and requests additional scans of her head, another admission for EEG monitoring, and a prescription for antiepileptic medication.

DISCUSSION

This vignette describes a presentation of PNES as an example of a complex and challenging patient-provider interaction in clinical neurology. The prevalence of PNES is as high as 33 per 100,000 in the general population. It is significantly more common among young women, often those with mental health disorders.¹ As with the patient in the vignette, individuals with PNES may have a substantial reduction in their functional capacity. Lack of ownership among providers of various specialties and denial of the diagnosis on behalf of the patient are complications of PNES, in addition to an underlying sense of powerlessness for both the patient and providers. Patients may seek third and fourth opinions, convinced they actually have occult disease. Many are placed on antiepileptic drugs, with their attendant side effects. Their peregrination leads to a delay in initiation of psychotherapy and pharmacotherapy directed at underlying anxiety and stressors, although responses to these treatments are variable.^{2,3} It is not uncommon, in a week of inpatient or outpatient neurology, to see a few patients who reject their diagnosis and request additional studies to complement the years of medical records they bring to the visit.

PNES patients like Susan exhibit a constellation of behaviors that fit what has been termed the demanding encounter.⁴ Examples outside of neurology include patients with viral upper respiratory symptoms who demand antibiotics, with chest pain from anxiety who demand a cardiac catheterization despite extensive negative noninvasive testing, or with fatigue who want a PET scan to look for cancer. These patients often see themselves as informed consumers who expect to receive requested interventions from their health care providers. They are more likely to challenge their physician and to view him or her as a competent technical expert who should provide the desired commodity.⁵ They are more likely to self-diagnose, to self-medicate, and to seek out a new provider if he or she does not achieve the desired outcome. They can provoke strong negative reactions in their physicians, particularly those who feel that their professional authority or judgment is being undermined.⁶

Bioethicists and physicians often consider the ethics of the demanding encounter to be clear. They emphasize the dangers of unchecked patient autonomy and focus on identifying

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principles or moral considerations that justify refusing the requested intervention.⁷ They discuss the importance of nonmaleficence, list potential complications from unnecessary diagnostic studies, invoke the moral value of professional integrity, stress the stewardship of medical resources, and suggest that the real problem is with tort reform so that physicians can stop worrying about the legal repercussions of refusals.^{8–11} While these arguments may provide a justification for providers to say no to specific requests, they neither elucidate the factors that underlie the demanding encounter nor do they help providers who want to find a way forward after they have made their refusal. We suggest, somewhat paradoxically, that respect for patient autonomy both justifies providers in saying no to unreasonable requests and explains how to make genuine clinical progress with patients like the one in the vignette.

The prevailing model of autonomy in Western medicine is based on a naturalist understanding of human action.¹² On the naturalist view—which finds its philosophical roots in Thomas Hobbes, David Hume, and Adam Smith—our choices are the product of 2 mental states: beliefs and desires.¹³ Our beliefs represent the way the world is and our desires represent the way we want the world to be. When beliefs and desires combine, they produce a choice, which leads to an action. To use a simple example, suppose John has been diagnosed with a glioblastoma. John's belief that he will have the best chance of being cured if he uses a research trial drug combines with his desire to be cured, leading him to enroll in a clinical trial. From belief and desire to choice to action; in principle, everything we do can be described this way.

Although the belief–desire theory of human action is primarily descriptive, it has been used—by John Stuart Mill,¹⁴ among others—to develop a theory of why some choices are “better” than others; namely, those in which our beliefs and desires are true. Take the case of beliefs. When my mental representation of the world is correct, I have true beliefs. Having false beliefs (i.e., false representations of the world) can lead to worse choices. For example, suppose that patients with glioblastoma actually have higher remission rates when treated with conventional therapy. John's decision to undergo experimental chemotherapy would be the wrong one, given his desire to be cured. He would be acting less autonomously than if he had all the right information. The case of desires is trickier. Since desires are a representation of how we want the world to be, it is harder to see how they can be true or false. How could you be wrong about what you want? First, we can clearly have desires that do not actually fit with other things we care about and, second, it can turn out that we do not actually want the world to be arranged the way we thought we did.¹⁵ For example, if, in order to be cured, John is left with severe neurologic impairment and can no longer interact with his friends and family, John may realize that he did not actually want to be cured. In this way, false desires can undermine our decision-making process.

When our beliefs are true and our desires are accurate expressions of what we really want, our choices are said to be fully autonomous. Inaccurate beliefs threaten our autonomy—this is why lying to someone (giving false beliefs) is believed to undermine autonomy. It is also why having other people tell us what we should want (indoctrination) or why having desires that we do not want (for drugs or alcohol, as in addiction) are seen as threats to autonomy.¹⁶ When patient choices are not autonomous—for example, a schizophrenic patient who believes that his health care providers are trying to kill him or when a health care proxy is

acting contrary to a patient’s expressed desires—we do not have to give them the same moral weight (although we do not necessarily have license to override them).

When we speak of respect for autonomous choices, we acknowledge that individuals are in the best position to judge what to believe and what to desire, but allow that we do not have to treat every choice equally. In the clinical context, we support autonomy by helping patients form true beliefs about medical interventions (the core of the informed consent process) and helping them understand how various outcomes and treatments affect their desires about quality of life and overall well-being (the core of shared decision-making). When we assess a patient’s capacity to make autonomous decisions, we assess his or her ability to form true beliefs (“Can you tell me the risks of leaving the hospital against medical advice?”) and make sure the decision under question is broadly consistent with his or her previously expressed desires (“Yesterday you said that you wanted to continue treatment and I just want to understand why you have changed your mind”). The weight physicians give to a patient’s decision hinges, in part, on whether he or she is acting autonomously.

This is particularly true when we are discussing choices, as in the demanding encounter, which require another party to do something for the agent rather than merely to leave the agent alone. An autonomous request for an intervention has considerably more moral weight than a request for an intervention that is being driven by an untrue belief or a false desire.¹⁷ In the demanding encounter, as we have described it, the patient’s request for additional testing or treatment cannot be described as fully autonomous because it is based on a false belief. It is not true that antibiotics will treat a viral respiratory infection, or that a cardiac catheterization will identify obstructive cardiac disease in a patient with atypical chest pain and a negative noninvasive workup. The desires behind these demands—patients want to feel better, to make sure that providers are not missing anything, to understand why their symptoms are persistent—are not problematic. Rather, patients in these encounters have incorrect beliefs about what is necessary for these desires to be fulfilled. This creates a space for physicians to help the patient achieve what he or she wants by correcting this belief. In this way, a model focused on autonomy can provide more resources than one focused on nonmaleficence or the importance of physician professional integrity.

Changing beliefs requires at least 2 steps: illustrating why the belief is an inaccurate representation of the world and replacing it with a more accurate view. Merely asserting that the patient is wrong is unlikely to be helpful. Instead, the physician should focus on the desire leading the patient to seek medical attention. This is not the desire for a specific treatment or additional tests—these desires are informed by the incorrect beliefs about what is happening—but the overall desire to feel better, to relieve pain, and to improve functioning. Once these desires are established as shared goals, the physician can focus on how to achieve them, using the best medical tools available rather than whatever intervention or test the patient believes is indicated. In this way, the patient may come to see the physician as engaged in a common project and make choices that help the patient get better. One reason patients are more satisfied when their providers order additional tests is that they feel like they are being taken seriously, and this is exactly what a framework built around developing fully autonomous choices promotes.

Applying this framework to the patient with PNES in the vignette, it is important to identify the broader desires that prompt her to continue seeking neurologic treatment. These may include the desires to be acknowledged for the truth of her suffering, to not be dismissed, to be given back control over her life, to be cared for, to be empathized with, and even to be validated that some aspect of her physical body and her life is not right and must be treated with the gravity it deserves. These are genuine representations of how she wants the world to be. However, her requests for additional testing and treatment—what she believes needs to happen in order for her desires to be fulfilled—are based on an incorrect belief about the underlying cause of her symptoms. It is not true that she has an occult brain tumor causing epileptic seizures or that frequent EEG monitoring or head imaging will diagnose structural

disease or will improve her symptoms. Rather than debate about whether these are indicated, her neurologist should focus on the desires that are leading her to seek more testing: the desire to find an alternative explanation for her symptoms and to start a treatment that will alleviate these episodes, to restore her previous level of psychosocial functioning, and to relieve some of the despair and frustration born from these episodes. The neurologist should review her clinical course and all previous studies with a specific focus on her level of insight into status and etiology of her own condition and what has led her to believe she has an undiscovered brain tumor. The neurologist should explain the diagnostic criteria for PNES and show her why this condition is a better explanation for her symptoms. The neurologist should review the outcomes for PNES patients with and without treatment, emphasizing that appropriate psychotherapeutic interventions have the best chance of helping the patient reach her goals. In this way, the neurologist may be able to reshape the patient's belief about why she is having these episodes and help her achieve her underlying desires.

We have suggested that, rather than casting the demanding encounter as requiring justification for physicians to override autonomous patient requests for unwarranted medical interventions, a proper understanding of autonomy provides resources for providers to engage with these requests and to help understand and achieve patients' underlying goals collaboratively. This is not, however, a claim that all patients with PNES will respond to this framework. Nor is the argument from patient autonomy intended to supersede other approaches to the demanding encounter. Some patients may respond better to a list of potential harms. Sometimes physicians will have to firmly decline further demands when a patient is not willing to consider alternative diagnoses or treatment options. Our experience, however, is that engaging directly with the patients' expectations for medical care—regardless of how consumerist they see their relationship with their physician—and treating them as agents capable of changing their beliefs about their own bodies is both more fruitful and more respectful.

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