Medical decisions are not just about the facts

What a life-threatening virus can teach us about empathy, psychology, and the practice of neurology

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Summary

Getting the facts about risk and benefit is a critical part of medical decision-making. But when doctors and patients disagree on what is reasonable risk, it takes more than a grasp of the data to establish the way forward. Our competence as physician-scientists relies on our ability to master the mechanics and information flow of our specialty. But we physicians, curious amalgams of scientists, scholars, researchers, and healers, should be aware of how we respond to the uniqueness of each of our physician-patient relationships, and be willing to explore ways in which the psychological and interpersonal dynamics influence the ethical, medically correct choices we pursue in them.

Recently, Fox and Rudick¹ offered the multiple sclerosis (MS) treatment community a valuable tool in the decision-making process concerning the use of natalizumab (Tysabri®, Biogen Idec). This drug, and other new and increasingly powerful therapies for the treatment of MS, confers a likelihood of benefit over previous therapies, but also a potential for unprecedented life-endangering side effects. The algorithm these authors have provided for computing the risk of progressive multifocal leukoencephalopathy (PML) will be an important part of the informed consent discussions that doctors have with patients considering natalizumab use.

This tool's potential benefit in clarifying quantitative risks is in keeping with the Food and Drug Administration's recent approval of revised wording for the drug's patient information sheet.² It now reflects the combined risks of duration on treatment, prior use of other immunosuppressant agents, and a positive test for the presence of antibody against the causative agent of PML, JCV virus. The problematic policy-mandated oversight of the process of monitoring the natalizumab-treated population for this rare but devastating iatrogenic complica-

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tion, and the difficulties the company and the MS community have had in collecting data which can be utilized in the decisions to use the drug, have been discussed by this author elsewhere.³

Although we are now empowered to better establish the facts of the risk/benefit equation for this therapy, it seems a good time to be reminded that such decision-making must also navigate the ways that patient and physician collaborate in the process of recognizing and sharing not just the facts, but also the feelings and motivations that each of them brings to risk assessment. In the following discussion, terms and ideas will be introduced that may seem foreign and unnatural to use in describing our work as neurologists and scientists. It may require some forbearance as the argument is made to imbed what is really clinical psychology in our work as physicians of the brain. The psychology of medical practice is now being taught as a subject in some medical schools, with textbooks now available to assist in the process.^{4,5} It is perhaps salutary to recall that neurology attempts to steward the part of the body most intimately connected to our selves as conscious entities possessed of intent, intelligence, feelings, and the capacity to communicate and control the body and its environment. Neurology may have a special responsibility in this context, especially if we agree with William Wiesel⁶ that the brain and its mind serves to mediate the expression and phenotype of the conscious organism, thus serving as the critical partner with the DNA level of control of what we are via genotype, in its expression and regulation of the adapting organism.

The term empathy, as related by Rifkin⁷ in his study of civilization and consciousness, *The Empathic Civilization*, is derived from the German *Einfühlung*, coined by Robert Vischer in 1872 and used in German esthetics. It relates to how observers project their own sensibilities onto an object of adoration or contemplation, and is a way of explaining how one comes to appreciate and enjoy the beauty of, for example, a work of art. Wilhem Dilthey borrowed the term and began to use it to describe the mental process by which one person enters into another's being and comes to know how that individual thinks and feels.⁷ Empathy plays a critical role in establishing the basis for the compassionate modern medical relationship.^{8,9}

Medical decision-making, facts, and feelings

It is increasingly clear from the literature on medical decision-making that so-called “facts”—defined as data derived from the scientific research literature about the disease or studying a therapy and its use in populations—are not the sole, or even the most powerful, factors in decisions on what constitutes reasonable risk.^{10–13} In research on what contributes to medical decision-making by doctors and patients, such “objective” data are often subordinated in the decision process to what are labeled “other factors.”¹⁴ In that literature, what

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these “other factors” are is often left unexamined, as they represent the difficult-to-measure, messy, emotional, spontaneous aspects of decision-making. Deciding their import and source is an area of considerable controversy: at least part of what Daniel Kahnemann¹⁵ calls fast thinking, analytic psychology calls the upwelling of unconscious contents—very different formulations of the complexity and intrapsychic sources of intuitive mentation. Notwithstanding this, as well as the glories Immanuel Kant and the philosophers of the Enlightenment saw in the new ruling role of Reason in the conduct of Man’s affairs, agreeing on the facts is not the way we 21st-Century citizens appear to actually establish veracity in medical decision-making. The answer to the question “what should be done for this patient/me?” is perceived through a valuation process, and the conditioning effects of this mental act on the relevant facts engage conscious and unconscious, rational and irrational, reasonable and unreasonable, logical and emotional tools possessed by both the doctor and the patient.^{16,17}

This observation may suggest that doctors lack only for compensatory strategies that enhance communication and education skills in conveying pertinent facts. But then, having acceded this point, a critical unmet issue presents itself: we cannot expunge the affective aspects of how both we and patients arrive at conclusions about the world and the medical care which is required in a given case. The question thus raised is not how we make these messy aspects of thinking go away, but rather how do we physicians learn to shepherd and moderate the relational process of reaching common ground on the value of facts and feelings, as it plays out in clinical practice?

To illustrate this, let us consider the following vignette. In the 2010 *Continuum* on Demyelinating Diseases, Jill Conway, MD, and this author presented a case in which doctor and patient disagreed on what constituted reasonable risk in the decision to use Tysabri.¹⁸ Briefly, a patient with MS is seen with a stable clinical course, but her brain MRI demonstrates new lesion formation. The doctor believes that the imaging results do not warrant a shift of therapy to a more risky one. The patient believes that it does, and specifically asks for natalizumab, even in the face of the risks for contracting PML.

Practicing empathic medicine when facts are not enough

How does a physician respond to a patient’s request for a treatment for which the physician cannot feel comfortable that the benefit is worth the risk, even after such formulae as Fox and Rudick offer are shared and understood? Redefining what is required to mediate disagreement between doctors and patients about reasonable risk is at the heart of why many of us became physicians. However, such nuanced interpersonal dynamics of patient care can be neglected due to our disinclination to practice psychology, perhaps, and characterological propensities that define our enthusiasm for such work (or the lack of it), but also, increasingly, the time and resource pressures of our practices. These demands have increased the seductiveness of the efficiencies promoted as “evidence-based medicine.”

Expanding on the 2009 *Annals of Neurology* editorial by Stephen Hauser and Clay Johnston,¹⁹ which elucidated the issues facing those who must weigh the risks and benefits of higher risk MS therapy like Tysabri, it is important to note that we are not just simply paying attention to preferences of our patients in this process. We are needing to concatenate objective and scientific evidence-based facts with the valuing subjectivity inherent in the psychologically rich, meaningful, empathic, and compassionate communication of the doctor-patient encounter. We know implicitly, but occasionally need to be reminded explicitly, that the

“right” choice for a given patient, in a particular setting at a particular time in that life, is not necessarily mandated by the literature, or a decision tree, or even by the physician’s experience with other patients.

Good doctors may listen to patients, acknowledge the power of the patient’s narrative, and realize the consequences of the biopsychosocial aspects of medical care. But even when this is done, and done well, we can still be left with a gaping discrepant chasm dividing us from our patients on critical issues such as reasonable risk. The role of the doctor in the relationship is psychologically complex, in ways incommensurate with that expected from an algorithmic approach to sharing the facts. This is at least partly because affect is owned and expressed by the patient, but also by the doctor, in different and more intimate, personal ways than are facts, and, despite protestations of denial, both are letting feelings and affect permeate their process of arriving at decisions about risk with which they are comfortable.

The natalizumab-associated PML risk typifies risk assessment in 2 ways: first, it demonstrates that such decisions are difficult to make in the absence of good data; but, as in our vignette, it also can be used as an exemplar of how one can arrive at different decisions on reasonable risk that are deriving from unconscious, irrational needs that have nothing to do with the data, but have a critical place in the process of these 2 people making that decision as a dyad, constrained by the social rules governing the professional alliance.

The doctor not only has to be aware of how these aspects of personhood come to the relationship; but as well, how to shepherd the process of reconciling the differences. A critical element in the counseling relationship is its asymmetry. Many see this exemplified in the model of the interaction characterizing the doctor as expert and professional, and the patients as suffering supplicants, in some inferior status when it comes to gaining control over the forces of the disease afflicting them. Models of doctor-patient relationships have of course gone far beyond such a simplification.^{20–22} But even in the most “equalizing” dually autonomous doctor-patient relationships, the treatment vector is mostly unidirectional (although every doctor knows of experiences with patients that turn this on its head, where the doctor feels the beneficiary of some healing process). When we are making recommendations for others, do the scales tip differently than when we are thinking of ourselves? How do the facts differ in those 2 situations? The doctor can ask himself or herself: do I establish reasonable risk differently for myself than for others? Could I recommend something I would not personally consider for myself?

The related question that we get more often is, “If this were your family member, Doctor, what would you do?” Many of us struggle to answer this well-meaning question. Though this seems to be a question about the risk, or the facts, it probably is not. It is more likely to be about the feelings and attachment the patients wish you to have with them, as if they were as important to you as your loved ones. They want to establish that the value of this decision has an emotional “common ground” on which they meet you.¹³ The clearest asymmetric aspect of the relationship is the potential risk—it is the patient’s life and wellness on the line, not the doctor’s. The doctor’s risks are less existentially challenging: things like self-confidence and self-worth, trust, integrity, honesty, competency, honor, reputation, income, and his or her own psychological health. But, true to our empathic capacity to feel someone else’s pain, doctors are expected to have honed a skill that combines their sagacity in the technical aspects of their field with a humanism that feels the touch of the patient’s soul on theirs. At that point, when the 2 participants disagree on something besides the facts, the question one might ask would be: what is it about the patient’s take on this situation, and on their life, that makes it important for them to disagree with me?

The divide between one’s self and that of the “Other” is at the root of what I am calling the psychological work we doctors do with our patients. In committing ourselves to it, we perform what James Marcum²³ elegantly calls “prudent love” in our practice of medicine. Unless we empathically process that information to establish how our characterological, temperament, and intelligence traits are serving us and our patients in this relationship, we will not be able to

allow participants on both sides to cross over the divide, and encounter each other in the meaningful fashion that can overcome such obstacles as we have described.

Learning and relearning how to listen and share facts and feelings in an evidence-based medical practice

How do we physicians know how to manage such interactions, and learn to better do so? Are we aware of, and able to work on, the psychological impact of such contretemps on ourselves, as well as on the dataset of our specialty area? And if these competencies are not in our skill set, can we still practice good medicine? What have we allowed our profession to become, if such goals are not among our key priorities?

It is important to consider whether such evidence-based decision instruments as those introduced for the Tysabri PML risk assessment lull us into a certain complacency concerning a possible pseudo-objectification of the process they advocate. Like all evidence-based medicine tools, its attractiveness is rooted in its ability to increase the efficiency of our work through elevation of factualness over the other aspects of decision-making. Although increasing the emotional distance between doctor and patient is likely the furthest thing from the minds of the well-intentioned authors of the Tysabri-PML algorithm, the ways that its use will play out in our hands will necessarily affect the psychodynamics of the clinical encounter. Any method of reducing our patient-encounter time, erroneously simplifying what may be inherently complex, puts us at risk of losing something precious that allows patients to know they are being cared for, and not just being the receptacle of care. Another way of saying this is that ownership of “the facts” has arguably monopolized the healing conversation, often to the detriment of the shared narrative.

Returning to our vignette, the physician in that situation emphasized with the patient that it was critical for them both to value her way of arriving at her decisions. Properly elucidated and clarified, the physician suggested that exploring the patient’s narrative could possibly suggest a solution to their disagreement on risk. In their subsequent discussions, the patient realized—with the doctor’s help—that the disagreement on risk was not just about the drug, or even the disease per se. The shared dilemma offered an opportunity for the discussion to move to a deeper level of motivation and intent. They discovered that underlying the ostensible issue of drug risk was the existential dilemma of the patient’s desire to control her life, and reconcile that need with other critical needs, feelings, and desires that were perhaps more difficult to identify and manage. They became aware that this decision involved how the patient shared her life and values with others, and how the relational dynamics arising from such interactions affected not just specific decisions such as the choice of her MS therapy, but also her capacity to deepen self understanding and insight. The discussion turned to issues of the patient’s sense of the vulnerability of her well-being, along with fears of loss of independence and power, a desire to have more children, the state of her marriage, the roles she played in her social constellations, attitudes about her employment, and her approach to psychological insight. The physician was able to reflect back to her how their shared approach to articulating these issues affected how the patient’s personal and medical choices were formed, as well as how she interacted with physicians and others in the process of establishing value and meaning. This interaction allowed a mutual reframing of the issues at hand, as well as a better understanding of the ways the doctor-patient relationship could facilitate and value such communication.²⁴

In this light, the ethical approach to establishing risk and benefit for a given patient is via an understanding of the conflicts and commitments, beliefs and expectations, fears and hopes operative in the patient’s psyche. Importantly, however, relational work goes both ways. In order to accomplish the task of bringing such insights back to the relationship, and reframing the decision process for the patient as it may be informed by such dynamics, the physician will likely also need to similarly try to understand what is driving him/her in the relationship with this particular patient, and how such issues of projection, transference, countertransference, trust, and emotional connectedness prioritize and value what is at stake.²⁴ Although the vignette speaks to a decision with profound ramifications on mortality and morbidity, the

relevance of the process I have described should not be limited by the severity of the possible consequences of decisions on risk. In the end, when the facts are shared and understood, but disagreements on risk persist, the problem is less about the actual risks, and more about the psychodynamics of health care.

CONCLUSION

Risk-benefit analyses, costs, and professional associations' manifestos of ethical standards for neurologic practice all merit consideration.^{25,26} Expanding the content and breadth of coverage of the MCAT examination to include a subtest on psychological, social, and biological foundations of behavior is a well-intentioned attempt to inculcate a sense of the psychosocial context in which health care takes place.²⁷ But it, and our education both in training and afterward, have emphasized behavioral science and the scholarly understanding of how health care functions in society, and neglected the tools required to bring these to bear in one's work with patients. It is critical to realize that such comprehension still leaves the doctor without the psychological tools with which to practice empathic clinical medicine. The new MCAT still cannot identify those with the capacity to do this work, arguably as critical to real success in our profession as anything else in the present curriculum. And nothing in our continuing educations as doctors allows us to "check in" and work on our capacity for psychological insight, either into ourselves or others.

Our competence as physician-scientists relies on our ability to master the mechanics and information flow of our specialty. But we physicians, curious amalgams of scientists, scholars, researchers, and healers, should be aware of how we respond to the uniqueness of each of our physician-patient relationships, and be willing to explore ways in which the psychological and interpersonal dynamics influence the ethical, medically correct choices we pursue in them.

REFERENCES

1. Fox RJ, Rudick R. Risk stratification and patient counseling for natalizumab in multiple sclerosis. *Neurology* 2012;78:436–437.
2. Biogen Idec. Biogen Idec Medical Information (MedInfo). Weston, MA: Biogen Idec; 2012.
3. Kachuck NJ. Registries, research and regrets: is the FDA's post-marketing REMS process not adequately protecting patients? *Ther Adv Neurol Disord* 2011;4.
4. Ayers S, Baum A, McManus C, et al. *Cambridge Handbook of Psychology, Health and Medicine*, 2nd ed. Cambridge, UK: Cambridge University Press; 2007.
5. Ayers S, de Visser R. *Psychology for Medicine*. London: Sage; 2011.
6. Wieser W. The role of the brain in human evolution. *Biological Theory* 2008;3:336–343.
7. Rifkin J. *The Empathic Civilization: The Race to Global Consciousness in a World in Crisis*. New York: Penguin Books; 2009.
8. Doyal L. The moral foundation of the clinical duties of care: needs, duties and human rights. *Bioethics* 2001;13:520–535.
9. Pellegrino ED. The medical profession as a moral community. *Bull NY Acad Med* 1990;66:221–232.
10. Heesen C, Kasper J, Köpke S, Richter T, Segal J, Mühlhauser I. Informed shared decision making in multiple sclerosis—inevitable or impossible? *J Neurol Sci* 2007;259:109–117.
11. Heesen C, Kasper J, Segal J, Köpke S, Mühlhauser I. Decisional role preferences, risk knowledge and information interests in patients with multiple sclerosis. *Mult Scler* 2004;10:643–650.
12. Kasper J, Köpke S, Mühlhauser I, Heesen C. Evidence-based patient information about treatment of multiple sclerosis: a phase one study of comprehension and emotional responses. *Patient Educ Couns* 2006;62:56–63.
13. Peters E, Vastfjall D, Garling T, Slovic P. Affect and decision making: a "hot" topic. *J Behav Decis Making* 2006;19:79–85.
14. Heesen C, Kleiter I, Nguyen F. Risk perception in natalizumab-treated multiple sclerosis patients and their neurologists. *Mult Scler* 2010;16:1507–1512.
15. Kahneman D. *Thinking, Fast and Slow*. New York: Farrar, Straus & Giroux; 2011.
16. Damasio A. *The Feeling of What Happens: Body and Emotion in the Making of Consciousness*. Boston: Harcourt; 1999.
17. Burton RA. *On Being Certain: Believing You are Right Even When You're Not*. New York: St Martin's Griffin; 2008.

18. Conway J, Kachuck N. Ethical perspectives in neurology: ethical considerations of when doctors' and patients' attitudes differ on risk aversion. *Continuum* 2010;16:225–228.
19. Hauser S, Johnston SC. Balancing risk and reward: the question of natalizumab. *Ann Neurol* 2009;66:A7–A8.
20. Parascandola M, Hawkins J, Danis M. Patient autonomy and the challenge of clinical uncertainty. *Kennedy Inst Ethics J* 2002;12:245–264.
21. Schneider CE. *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*. New York: Oxford University Press; 1998.
22. Emanuel E, Emanuel L. Four models of the physician-patient relationship. *JAMA* 1992;267:2221–2226.
23. Marcum J. The role of prudent love in the practice of medicine. *J Eval Clin Pract* 2011;17:877–882.
24. Kachuck N. When neurologist and patient disagree on reasonable risk: new challenges in prescribing for patients with multiple sclerosis. *Neuropsychiatr Dis Treat* 2011;7:197–208.
25. American Academy of Neurology. *AAN Code of Conduct*. St. Paul: American Academy of Neurology; 2009.
26. Council on Ethical and Judicial Affairs of the American Medical Association. *Principles of Medical Ethics*. Chicago: Council on Ethical and Judicial Affairs of the American Medical Association; 2001.
27. Kaplan R, Satterfield J, Kington R. Building a better physician: the case for the new MCAT. *N Engl J Med* 2012;366:1265–1268.

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