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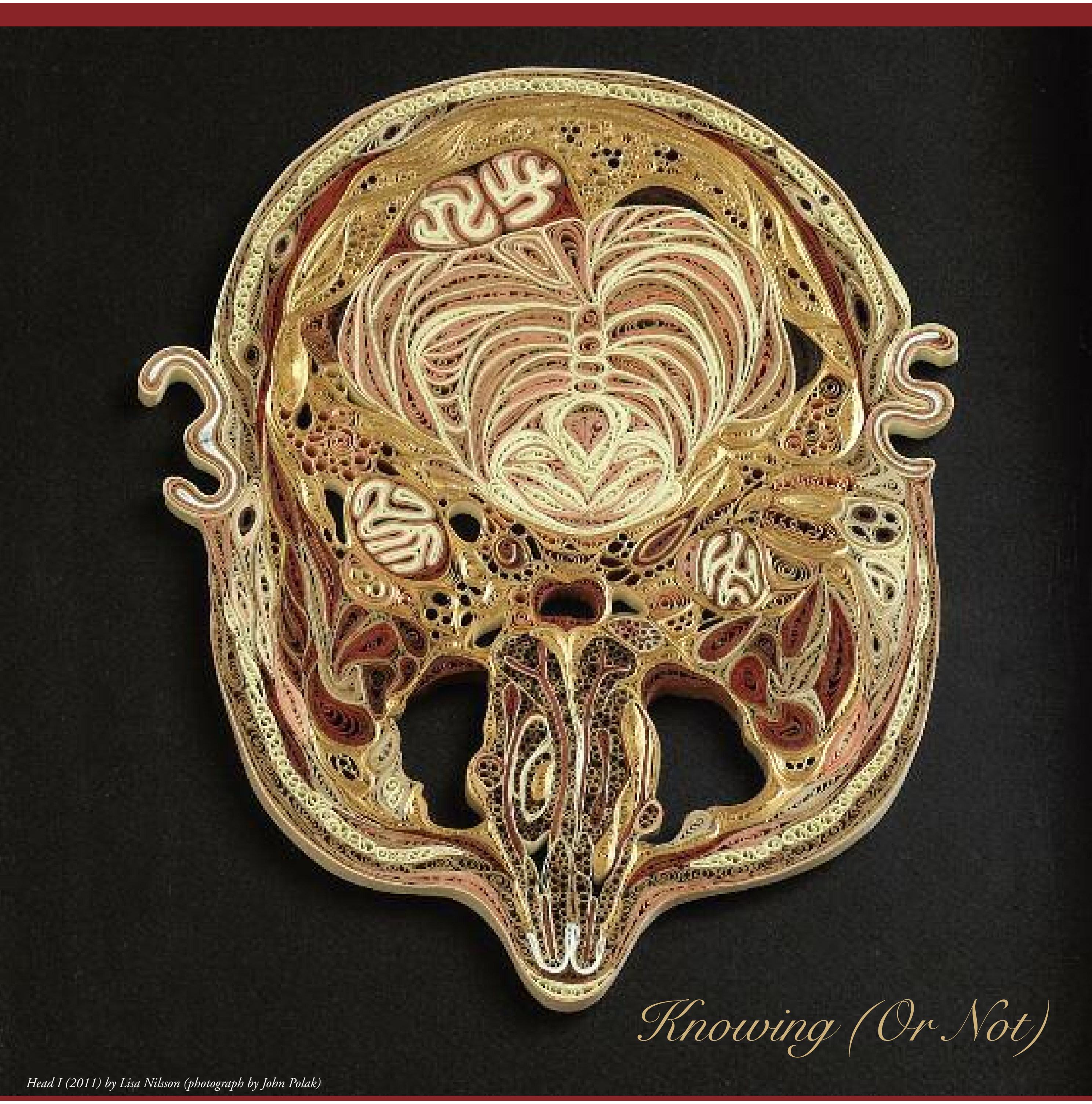

Knowing (Or Not)

Head I (2011) by Lisa Nilsson (photograph by John Polak)

A publication of the Medical Humanities and Bioethics Program, Northwestern University Feinberg School of Medicine

About the Cover: *Knowing (Or Not)*

"I have *such* an advantage on a nude beach," Kathryn Montgomery once announced. Her brain is like a pinball, rapidly bouncing between multiple referents until it zigzags to a seemingly unconnected sentence. The fun is in asking her to connect the dots: "What?" we shriek. "I'm nearsighted, so I wouldn't have to see all the dilapidated flesh." Ah yes, we were comparing glasses prescriptions—and suddenly the conversation is much more interesting. I think of Kathryn as the Amelia Bedelia of the academy, because the unique way her mind works generates disruption and delight. Her novel perspective is the wellspring of her enormous intellectual contributions, and that's what's celebrated in this issue of *Atrium.*

Professor Montgomery has been an integral part of Northwestern medical school's Medical Humanities & Bioethics Program for twenty-five years. She was Co-Director or Director for twenty-one of those years, and in 2011 she received an Endowed Chair and became the Julia and David Uihlein Professor of Medical Humanities & Bioethics. Kathryn's legacy is programmatic as well as intellectual: when she arrived in 1988 it was just she and Jim Bresnahan, the JD-PhD Jesuit priest who founded the Program. Now the Program has grown to the vibrant group below, the energy of the primary MH&B faculty is devoted to scholarship and teaching (for example, our M1 medical students now have 46 hours of required ethics and humanities content), and no primary faculty salaries depend on grant dollars. Kathryn now teaches half the year, and plans to retire this fall. She rejected our suggestion of an *Atrium* Festschrift to mark this event, but she was excited by the idea of reading what selected scholars were thinking about her consuming interest—what we know and how we know it. So in addition to unsolicited pieces accepted in response to the announcement of theme, this issue includes a large number of solicited pieces. (As a result of Kathryn's choices, I'm pleased this issue of *Atrium* features our first European voices. I chose to contravene editorial convention by leaving their European spellings intact—it seems like an element of voice, and I wanted you to hear their accents as you read.) The invited authors did exactly as Kathryn insisted they be instructed: either cite or discuss her work, or feel free to not mention it all.

To be sure, Kathryn's ornate answers to seemingly straightforward questions are the opposite of literal, linear Amelia's. Once I was invited to spend days at another institution with a host I'd never met, so I checked him out with Kathryn: "Is X a good guy?" "Well! His grandfather was the first person in that city to …" the story began, and it was a long one. As it wound through multiple people, places, and times, the impatient lawyer half of my brain thought, "What do I need to know about his grandfather? That was a yes-or-no question!" Then it hit me: fish soup. *The Spirit Catches You And Then You Fall Down* tells the story of a Hmong student who chose the recipe for fish soup as his topic for a five minute oral report, then spent forty-five minutes creating a "piscatory flowchart" of how to catch, clean, and cook a fish, all illustrated with anecdotes from his own fishing experiences. Author Anne Fadiman uses this story to capture the essence of the Hmong, explaining that they have a phrase often used at the beginning of an oral narrative that reminds listeners "you can miss a lot by sticking to the point." I suddenly understood Kathryn's Southern storytelling in a new way—"yes" or "no" is an impoverished response when the true answer to any question is a complex tapestry.

That's why artist Lisa Nilsson's extraordinary *Head I* (2011), a life-size representation of a lateral section through the head at bridge-of-the-nose level, seemed a fitting cover. Ms. Nilsson makes intricate anatomical cross-sections of surprising beauty with a time-intensive, detail-oriented technique called "quilling." This involves rolling and shaping narrow strips of paper—in the case of Ms. Nilsson's Tissue Series, Japanese mulberry paper and the gilded edges of old books. Quilling was first practiced by Renaissance nuns and monks who are said to have made artistic use of the gilded edges of worn out bibles, and later by 18th century ladies who made artistic use of lots of free time. In Ms. Nilsson's free time, she became a Certified Medical Assistant in 2010. "I love how asymmetrical the body looks in cross section," Ms. Nilsson says. "We are so symmetrical on the outside and so asymmetrical on the inside and everything inside fits so perfectly. This is the connection I made to quilling. Rolled pieces of paper are amenable to being squeezed, shaped and shifted to fill a space. I find quilling exquisitely satisfying for rendering the densely squished and lovely internal landscape of the human body in cross section."

Katie Watson, Editor

To see more of Lisa Nilsson's work or to contact the artist, visit http://lisanilssonart.com

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THE CRITICAL VOCATION OF THE ESSAY—

EVEN IN PROFESSIONAL DEVELOPMENT

Barry Saunders, MD, PhD

Among the "literature and medicine" professoriate, Kathryn Montgomery has managed the most marvelous yoking of literary studies with philosophical and anthropological sensibilities. She has not ceased to address, throughout her career, specific genres of expression—rhetorical forms—that constitute medical ways of thinking and knowing. Anecdote, case, aphorism, rule, maxim… Among other things, these revise the dominion of "narrative" in significant ways.

What follows are some reflections on yet another rhetorical form that has special affinities with medicine: the essay. My reflections are summoned in part by the increasing emphasis in worlds of medical curriculum on "professionalism." Many advocates of professionalism are emphasizing students' proper behavior, and phased accommodation to professional roles—their normative development as responsible physicians. Episodes of this development are documented in portfolios of students' "essays" reviewed by medical school faculty.

My question: how do essays of professional development fit with the vocation of the essay as a genre?

Essaying is more than writing nonfiction within particular length parameters. As we know from Montaigne, 16th-century originator of the genre, the essay is about trying, from *essayer*—cognate with assay—so also, weighing, testing, being put to tests. Medical students are familiar with tests, but largely as means to an end: knowledge, or "competence." Essays, at their best, are about something else.

Reproduction in quadrichromy of the Specimen of Bordeaux of Essays of Montaigne, ed. Philippe Desan (Fasano-Chicago: Schena Editore, *Montaigne Studies,* 2002; Garnier classics, 2011).

Essays that enticed me into medicine included physician Lewis Thomas's, from the *New England Journal of Medicine,* collected in *The Lives of a Cell.* I remember one meditation on endosymbiosis: Thomas fretted that his mitochondria were alien life forms, and that they might be running the show—his show. Strangers, comprising maybe half his dry weight, mocking his presumption of self-identity—"operating a complex system of nuclei, microtubules, and neurons for the pleasure and sustenance of their families, and running, at the moment, a typewriter."[1] What a marvelous inversion of anthropocentrism—and of competence![2]

Montaigne's essays were written in the first person and always enfolded personal experience—distinguishing the essay genre from the "compendium of adages."[3] They were written in French, reaching across class hierarchies. Their composition was unsystematic. They endorsed inquiry over knowing. And they were constantly under revision.

The page on the right, from a copy of the last edition of Montaigne's Essays published during his lifetime,[4] is annotated in Montaigne's own hand. Revision and change were part of Montaigne's concept of self: to essay was to test himself, engage in dialogue with himself, encounter himself *in flux.* And not merely self: the essay staged a conversation with a range of classical interlocutors on his library shelves (especially the Stoics), with his lost friend la Boetie, with death.

Montaigne's low opinion of physicians—"their dogmas and magisterial frowns"[5]—is famous. Medical students may rationalize this as a function of the sad state of medical knowledge in the early modern period, but we do well to consider his indictments of therapeutic presumption and iatrogenic illness in our historical moment as well. Montaigne is deeply skeptical about therapeutic intervention writ large, about its inevitable interference in experiences of change, suffering, and dying. "To philosophize," Montaigne memorably observed (after Cicero and Socrates), "is to learn to die."[6] But both are difficult commitments to incorporate into today's potent institutional ethos of: not on my shift! In any case, the birth of the essay implicates some of the most potent critique of the medical enterprise ever written.

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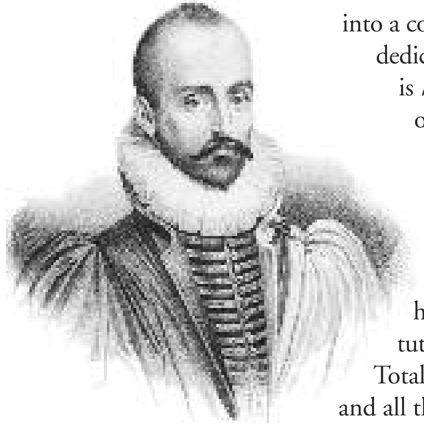

Since Montaigne, throughout modernity, the essay has renounced straits and rigors of disciplinary genres—eschewing systematicity, or pretensions to cumulative certainty.[7] The essay's thinking emerges from particulars rather than generalities.[8] Nor is there necessarily a narrative arc or *telos:* as cultural critic Theodor Adorno noted, in the "force field" of the essay, "[t]hrough their own movement the elements crystallize into a configuration."[9] Literary historian Georg Lukács called the essay "too… independent for dedicated service."[10] Adorno was more emphatic: "the law of the innermost form of the essay is *heresy.* By [its] transgressing the orthodoxy of thought, something becomes visible in the object which it is orthodoxy's secret purpose to keep invisible."[11] The "form" of the essay for Adorno is an unexpected constellation among objects and concepts that escapes protocol, resists dogma, draws back veils on received wisdom.

Why should the essay's resistance to protocol be of concern for trainers or trainees in medicine? Because the hospital, seat of so much of medical training, is not merely a place with a few protocols; in sociologist Erving Goffman's comparative analysis, hospitals are—along with prisons, monasteries, and bootcamps—exemplars of "total institutions."[12] When Goffman coined this term in the 1950s, total resonated with "totalitarian." Total institutions dictate ways of thinking and behaving: all inhabitants have assigned roles, and all their needs are supplied. Medical professionals and trainees are among these inhabitants. "In most total institutions… most inmates take the tack of what they call playing it cool. This involves a somewhat opportunistic combination of secondary adjustments, conversion, colonization and loyalty to the inmate group, so that… the inmate will have a maximum chance of eventually getting out physically and psychically undamaged."[13]

Fortunately, Goffman articulated (elsewhere) another capacity for individuals functioning in organizations: "role distance." This names the ability we all have to resist being fully co-opted by our roles. Role distance is what an eight-year old discovers on the merry-go-round when she affects standoffishness about her ride, feeling a little too old to be a princess clinging to her loyal horse in quite the enthusiastic way a four-year old does. In Goffman's terms, to exercise role distance, at whatever stage in life, is to look at one's assigned role critically, skeptically. Even, for a moment, *with disdain.*[14]

So role distancing is a reflexive exercise, a form of self-examination and resistance. To think critically about one's role does not require attribution of malevolence to the powers resisted—though that can be helpful in total institutions. It can simply be a heuristic device, a claiming of flexibility and imaginative freedom. There is no index or metric of cooptation that calls it up. Claiming such distance might hinge on sensing a kind of danger—perhaps especially the danger of enthusiasms of conviction.

Thinking critically: what does this really mean? Political philosopher Judith Butler has written a lovely essay on critique, tracing some of its conceptual genealogies. Butler cites cultural historian Raymond Williams to clarify that critique is not, as is popularly assumed, mere fault-finding, and not a swift rush to judgment: rather, it entails suspension of judgment.[15] She cites Adorno in clarifying that critique is a mode of engagement with *particulars*—so, always situated, never an abstract position. Critique is a *practice.* Yet as practice, critique is not focused solely on the object of criticism (nor mere exhibition of the critic's expertise). For Butler, critique is, at its core, a questioning of the very categories that enable its own practice.[16]

This brings Butler to a reprise of philosopher Michel Foucault's essay "What is Critique," and what he refers to as "critical attitude." There are two features of this critical attitude to mention here. One is its relation to modalities of *government:* critical attitude names a disposition to ask "how *not* to be governed"—not to be an anarchist, to render oneself radically ungovernable, but to ask a more situated and engaged question: "How not to be governed like that, by that, in the name of those principles, with such and such an objective in mind and by means of such procedures, not *like that*, not for that, not by them."[17] The second feature is Foucault's assimilation of this critical attitude to *virtue.* This is something of an enigmatic claim. Foucault links this virtue to modalities of self-knowing and self-styling especially apparent in Reformation resistances to Churchly dogma and monastic discipline. "Critique is the movement by which the subject gives himself the right to question truth on its effects of power and to question power on its discourses of truth."[18] Foucault also links this virtue to the *courage* figured in the Enlightenment motto of philosopher Immanuel Kant, "dare to know"—which entailed inquiry into the conditions of knowing, the limits of knowing. In the knowledge regimes of medicine, such inquiry takes courage indeed!

Foucault's essay on critique reflected on Kant's famous essay, "What is Enlightenment?"[19] Enlightenment is, in Kant's formulation, a people's escape from tutelage toward free exercise of reason. This was among other things a claim about literate persons' privilege, and responsibility, to think in public. The functionary thinking on behalf of an employer or administrator is engaged in a "private" use of reason, and therein obliged to obey the rules. But in our "scholarly" vocation—as writers addressing a cosmopolitan readership, in journalistic writing or in academic journals—we may engage in public exercise of reason, which must be free to question, to object, to propose improvements.[20] Of note, for Kant, "public" did not imply the state. The state is one of the sovereign powers that provide people with offices and official duties. In the University of Kant's day, the "higher" Faculties—of medicine, law, and theology—were constrained in their exercise of reason by agendas of state, monarch, and church. Only the "lower," "philosophical" Faculty was in Kant's view able to exercise freedom of thought, to think in and with a *public*—indeed, sometimes about how not to be governed—unfettered by external authorities and by the enticements of thought's private uses.[21]

Medicine today remains an institution of tutelage, bound to instrumental utilities of the state, deeply informed by dogmas and by priestly authority. So how can medical training comport with Kant's sense of public freedom? This is difficult. Doctors, like all professionals, are granted monopoly over their learned practice by the state, on condition that they serve social goods. Physicians and physician-scientists seek, indeed compete for, state and princely funding—enticements and fetters that can easily privatize, in the Kantian sense, the critical exercise of reason.

THE VOCATION OF THE ESSAY IS CRITIQUE. FREEDOM FROM TUTELAGE. EMERGENCE, NOT MASTERY, EVEN FOR PROFESSIONALS IN THE MAKING. HERESY.

Foucault's emphasis on questioning the conditions of our knowing echoes Kant, but it is also animated by the more Nietzschean project of daring to know otherwise. There is a radical embrace of uncertainty and of emergence here. How to put this into practice in the powerful knowledge regimes of medicine and medical training? This returns us to essaying. Essaying is a fairly familiar practice in humanities, in qualitative social sciences, in "human sciences." Yet how does the essay fit into teaching agendas in medical schools, into training regimes seeking compliance with norms of behavior and competence? Can essaying in professional development be a vehicle for, or extension of, experiences of role distance?

Fortuitously, one of the "competencies" medical schools have begun to seek is "critical thinking." Yet there isn't much agreement about what this means. Some of it is about skills of evidence-based practice—mastery of protocols for distinguishing good from bad evidence. Too little of it is about questioning how evidence and knowledge is historically conditioned, networked, and produced in agonistic fields—"questioning of power on its discourses of truth." And there is even less agreement about how critical thinking should be taught. Perspectives and methods from humanities and social science disciplines—Kant's "lower" Faculties—seem necessary, and they do find service in many medical schools.

For instance: over the last decade, several colleagues and I have conducted some seminars with medical students and graduate students together. In one format, eight MS2s and eight graduate students from disciplines including literature, anthropology, and religious studies, and occasionally even other professional schools (law, education, social work), gather at the same table for a semester. Aspirants to "higher" Faculties alongside those to "lower." In my seminars, medical students are aboard for about 26 hours a term and grad students for the usual 40; medical students read about 30 pages a week and grad students a book or so. These seminars are challenging to conduct, but they often go remarkably well and are the most fun I have as a teacher. To find sharable language—crucial for a reading "public"—I ask students to explain long words and precious concepts to each other. Discussions often bear a mix of skepticisms, pragmatisms, disciplinary frictions, and translations. The readings collated in a syllabus are, at the outset of a seminar, a kind of connect-the-dot puzzle whose contours only become clear in the force-field of the cross-disciplinary seminar table. Like an essay.

In these and most other humanities and social science classes (mine and those of colleagues in many medical schools), students also write essays. Not treatises, not lists, not true/false choices, not causal chains, not tables of statistical correlation; essays. Apart from thinking out loud in conversation, essays may be the best way for students to demonstrate their capacities to combine and compare concepts; to weigh sources in terms of genre, rigor, and persuasiveness; to generate interpretations, frictions, and syntheses; to relate particulars to generalities; to embrace uncertainty; to qualify agreement or disagreement; and to think reflexively. Faculty members who read these essays are listening hard for forms of critical engagement. Some students hate writing essays, of course. Some of them yearn for the comforts of a multiple-choice exam—in service of positive knowledge. Some demand to know just how essaying will make them better doctors.

As if in answer to this last question, lately "reflective essay" assignments have multiplied within the clinical training of these same medical students. This too is happening at many institutions. Short essay assignments crop up in clerkships, under the sign of "professionalism" especially—a quality that clerkship directors are at pains to demonstrate that they can both teach and evaluate. In some places these "essays" are as brief as a couple of paragraphs—a napkin-scrawl. And many are read rather glancingly, perfunctorily: how many clinical faculty members have been trained to read student writing closely and provide substantive commentary? Some of these essays wind up folded into professionalism portfolios, as markers of normative professional development. It is hard to imagine these conditions are likely to foster the freedoms that are the essay's historical province. My concern is that essays of professional development are at high risk of being pressed into the service of "private" thinking, under the restricted tutelage of the "higher" Faculty of medicine and its evaluation-bureaucracy—not the fostering of role distance, not contributions to a more cosmopolitan and "public" sphere of critique.

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If we really want medical students to learn to think critically—and for "professionalism" to recover its sense of an examined life—we may need to return to essaying in the shadow of Montaigne's suspicions of professional authority, and his discovery of selfhood in wider conversation. How can we encourage students to exercise critical capacities freely? To voice concerns about the profession itself, the cultures in which it operates, or the powers, limits, and risks of its ways of knowing? Kathryn Montgomery has noted the proximate relations some medical schools have with their parent universities: perhaps we can make better use of these relations.[22] Perhaps we could recruit readers of "professionalism" essays from other, non-medical disciplines—or even from medicine's clientele, its laity. Perhaps we could expand the special training offered in some places to these essays' more medicalized readers.[23] Perhaps we could develop our faculties' capacities to teach how we know, how at times we un-know, and how new knowledge and new mastery produce new uncertainty. In any case, readers of essays of professional development need to be able to put professional norms and proprieties in brackets occasionally—to become connoisseurs of sassiness, insubordination, and various other prisings of role distance that student essays might articulate. If student writings within a normative process of professionalization are to call themselves essays, they should be allowed and encouraged to make balky gestures, to be meandering, interruptive… to be revised... and to imagine, if not to find, readerships outside the guild—in a *public* space.

The vocation of the essay is critique. Freedom from tutelage. Emergence, not mastery, even for professionals in the making. Heresy.

Barry Saunders is a physician trained in general internal medicine as well as an anthropologist of biomedicine with a doctorate in Religion & Culture. When he met Kathryn Montgomery in 1985, she helped nudge a crucial pendulum swing between his biomedical training and his humanities training. He is now on the faculty of the UNC Department of Social Medicine with appointments in several Arts & Sciences departments. These remarks (indebted to discussions with Professor Ruel Tyson) were adapted from a recent lecture to the 4th National Conference for Physician-Scholars in the Social Sciences & Humanities (Chicago, April 2011): "Essaying Critique in a Total Institution." Barry_Saunders@med.unc.edu

[1] Thomas, Lewis. "Organelles as Organisms," *The Lives of a Cell* (New York: Viking Press, 1974), 69-74; 72.

[2] I was charmed but unsurprised to find an essay by Thomas ranked in the top five of an empirically-derived "essay canon" in US undergraduate education: Bloom, Lynn. "The Essay Canon," *College English* 61:4 (March 1999), 401-30; 426.

[3] Good, Graham. "The Essay as Genre," *The Observing Self: Rediscovering the Essay.* (London: Routledge, 1988), 1-25; 1-3.

[4] Page from *Exemplaire de Bordeaux,* Bibliothèque Nationale de Bordeaux, reproduced in *Yale French Studies* 64 (1983).

[5] Montaigne, Michel de. *The Complete Essays of Montaigne,* trans. Donald Frame (Stanford: Stanford Univ. Press, 1958). "Of Experience," 835.

[6] Montaigne, "That to Philosophize is to Learn to Die," *The Complete Essays of Montaigne,* 56-67.

[7] Good, "The Essay as Genre," 4-6.

[8] In analytic terms used in Kathryn Montgomery's own work—e.g. "A Science of Individuals"—the essay's thinking privileges the "idiographic" (singular cases) over the "nomothetic" (law-bound). Montgomery Hunter, Kathryn. "A Science of Individuals: Medicine and Casuistry," *Journal of Medicine & Philosophy* 14 (1989), 193-212. Kauffman, R. Lane, "The Skewed Path: Essaying as Un-Methodical Method," Diogenes 36 (1988): 66-92; 234. These terms originated with Wilhelm Windelband (1894) and Wilhem Dilthey.

[9] Adorno, T.W. "The Essay as Form," trans. Bob Hullot-Kentor and Frederic Will, *New German Critique* 32 (Spring-Summer 1984), 151-71.

[10] Lukács, Georg. "On the Nature and Form of the Essay: A Letter to Leo Popper," *Soul and Form,* trans. Anna Bostock (Cambridge, MA: MIT Press, 1974 <1971>), 1-18; 15.

[11] Adorno, "The Essay as Form" (1958). My emphasis.

[12] Goffman, Erving. "On the Characteristics of Total Institutions," *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Garden City, NY: Anchor Books, 1961), 1-124.

[13] Goffman, ibid., 64-5.

[14] Goffman, Erving. "Role Distance," *Encounters: Two Studies in the Sociology of Interaction* (Indianapolis: Bobbs-Merrill Co., 1961), 85-152; 105-10. The merry-go-round example is his own.

[15] Butler, Judith. "What is Critique? An Essay on Foucault's Virtue," in *The Political: Readings in Continental Philosophy* (London: Basil Blackwell, 2002), 212-26; 212.

[16] Butler, ibid., 213ff.

[17] Foucault, Michel. "What is Critique?," trans. Lysa Hochroth, in *The Political: Readings in Continental Philosophy* (London: Basil Blackwell, 2002), 191-211; 193 (emphases in original).

[18] Foucault, ibid., 194.

[19] Foucault, ibid., 194-200. Kant, Immanuel. "What is Enlightenment?" *On History,* ed. Lewis White Beck, trans. Lewis White Beck et al. (Bobbs-Merrill, 1963), 3-10.

[20] Kant's essay was published as a newspaper article. See Foucault, ibid., 194.

[21] Kant, Immanuel. *The Conflict of the Faculties,* trans. Mary Gregor (New York: Abaris Books, 1979). (Compare Montaigne, two centuries earlier, disavowing any profession but self-inquiry: "I readily excuse myself for not knowing how to do anything that would enslave me to others." ["Of Experience," 825].)

[22] Curry, Raymond H. and Kathryn Montgomery, "Toward a Liberal Education in Medicine," *Academic Medicine* 85:2 (February 2010), 283-87.

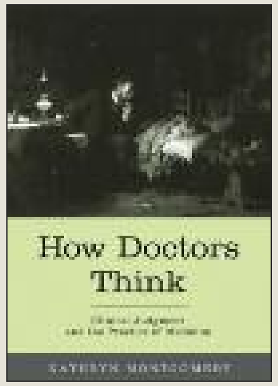
[23] The imaginative capacities and tool-kits of "narrative medicine" are important here—though I mean to be clear that the essay is not an intrinsically narrative genre. Indeed, the essay may have its strongest affinities with dialogue/dialectic—in principle open-ended, often meandering. See Kauffman, "The Skewed Path," 70, citing Pater.

On Explaining Medicine to Itself

Howard Brody, MD, PhD

Kathryn Montgomery is one of today's foremost philosophers of medicine. We are indeed fortunate that she has never allowed her lack of a philosophy degree to cramp her style, because *How Doctors Think* is both a philosophical and an interdisciplinary tour de force, seamlessly interweaving personal narrative with a shrewd assessment of the nature and meaning of medical evidence.

I was reminded of Kathryn's earlier contributions to our field when I inherited a graduate seminar, "Humanism and the Medical Humanities," from my eminent predecessor, Ron Carson. Some of the older students informed me that the course, as Ron had taught it, was perfection itself, and that I dared not alter a single reading. The course is bookended by two articles which I believe were both orations before the old Association of Faculty in the Medical Humanities (a part of the Society for Health and Human Values, which later merged into the American Society for Bioethics and Humanities). In 1984, historian Daniel Fox spoke on "Who We Are," and Kathryn followed up (I would guess in 1986) with "What We Do." My current seminar students said that had they only read the final week's readings (including Kathryn's) at the beginning, the seminar would have made much more sense.



The "What We Do" talk says a great many good things (besides providing us with a useful snapshot of the field of medical humanities in the US in that era), but its most important passage is: "This is where we come in. All of us are engaged in the philosophy of medicine: we explain medicine to itself. To ourselves, to the world. The imperiled place of medical education in the university, and indeed, medicine's survival as one of the intellectual disciplines depend in some part on what we do." (377)

Recently, our medical humanities program in Galveston was debating the adoption of a new mission statement, and I proposed, "We explain medicine to itself." Several of my colleagues immediately attacked this proposal. They did so for a couple of reasons. One was that they love to argue with anything that I, or anyone else, proposes; we require this trait of all potential faculty candidates before we will grant them an interview. The second reason was that they believed the good will and collaboration of physician faculty are critical to our success, and they feared a mission statement suggesting that they would have no idea what they did unless we explained it to them would antagonize and insult these potential collaborators.

Kathryn, as usual, was way ahead of us, because she introduced the passage above with: "Because illness and health care have become the arena of modern moral choice, the interpretation of medicine is a somewhat larger task than can be undertaken along with its everyday practice. Moreover, medicine itself has no special duty of self-examination and reflection." (377) Actually, the last statement is incorrect if we accept Donald Schön's idea of the reflective practitioner, but Schön's ideal practitioner reflects in a different way and on a different level than the reflection on medicine offered by the humanities. The basic point is that we do not insult our medical (or scientific) colleagues if we suggest that explaining medicine to them is what we are about. It's a division of labor, crudely put. If they wish, they are more than welcome to join us in explaining medicine to itself, and their input will be greatly valued. But the day-to-day work of clinical practice, or even the day-to-day work of teaching medical students, *does not* include explaining medicine to itself in the important sense Kathryn had in mind.

When those of us in the medical humanities wonder what we are about, we could do much worse than to return to Kathryn's words, and realize that above all we are here to explain medicine to itself. Kathryn has been doing her level best at this for several decades, and welcomes our company.

Howard Brody is a family physician and philosopher who currently serves as the Director of the Institute for the Medical Humanities and the John P. McGovern Centennial Chair in Family Medicine at the University of Texas Medical Branch, Galveston. He is the author of The Healer's Power *(1992),* Stories of Sickness *(2003), and* The Future of Bioethics *(2009). habrody@utmb.edu*

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Good doctoring:
have we replaced reason with rationality?

Trisha Greenhalgh, OBE, MA, MD, FRCP, FRCGP, FFPH, FSB,

The essence of good doctoring is summed up in the motto of the UK Royal College of General Practitioners: *cum scientia caritas,* "loving care with expert knowledge" (www.rcgp.org). This motto upholds the professional ideal of delivering the highest quality bioscience while also attending to the human needs of the patient.

Whilst the *scientia* component of good doctoring is often equated with evidence-based medicine (EBM), the original definition of EBM actually incorporates *caritas* too. However, because only the first sentence of the definition of EBM is generally quoted, many do not realize that EBM was acknowledged by its original protagonists as being dependent on clinical judgement and contingent on patient choice. The full definition is reproduced below:

> Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. **The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice. Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care.** By best available external clinical evidence we mean clinically relevant research, often from the basic sciences of medicine, but especially from patient centred clinical research into the accuracy and precision of diagnostic tests (including the clinical examination), the power of prognostic markers, and the efficacy and safety of therapeutic, rehabilitative, and preventive regimens. (Sackett et al., 1996: 71, emphasis added)

The best treatment is not necessarily the one shown to be most efficacious in randomised controlled trials, but the one that fits a particular set of individual circumstances and aligns with the patient's preferences and priorities. Early research in EBM focused on the epidemiological *(scientia)* component and sought to build an evidence base of randomised controlled trials and other "methodologically robust" research designs. Later, a tradition of "evidence-based patient choice" emerged in which the patient was assumed to be a (more or less) rational chooser and the clinical challenge was framed as how to convey the research evidence about different treatment options in a way that supported informed patient choice (Edwards and Elwyn, 2009). But the third component of EBM—individual clinical judgement—has not been extensively theorised by scholars within that tradition.

One of Kathryn Montgomery's many enduring contributions to the medical literature was to draw on Aristotle's notion of *praxis* in analyzing clinical practice as an example of case-based reasoning (Montgomery, 2006). Medicine is governed not by hard and fast laws but by competing maxims (rules of thumb). The essence of judgement is deciding which (if any) rule should be applied in a particular circumstance. Clinical judgement incorporates science (especially the results of well-conducted research) and makes use of available tools and technologies (including guidelines and decision-support algorithms that incorporate research findings). But rather than being determined solely by these elements, clinical judgement is guided ultimately by the practical and ethical question "what is it best to do, for *this* individual, given *these* circumstances?"

The dual commitment to *scientia* and *caritas* has been analysed from a philosophical perspective by the Norwegian family physician and philosopher Edvin Schei. The former, he suggests, requires the practitioner to consider the objective patient—that is, the patient as expressed in terms of measurements and standardised procedures, for which objectively-assessed diagnostic tests and treatments are then considered. The latter, in contrast, requires attention to the existential patient—that is, the patient's subjective experiences and human needs (Schei, 2006). The concepts of evidence-based (that is, rational, objective) patient choice and shared decision-making can be incorporated in the *objective* component of good clinical practice. But there are also *subjective* (and intersubjective) aspects of the interaction to consider.

Unlike disease, which can be defined in terms of a typical constellation of symptoms, signs, and test results, *illness* is a personal, lived experience that is both emotionally laden and socially meaningful (for example, it may come with various connotations of shame and blame) (Scambler, 2009). The good clinician engages reflexively with this lived experience and acts not merely as diagnostician or technical expert but also as active listener (Frank, 1998) and "professional witness" (Berger and Mohr, 1997). Using Schei's definition, good doctoring is *"a relational competence, where empathic perceptiveness and creativity render doctors capable of using their personal qualities, together with the scientific and technologic tools of medicine, to provide individualized help attuned to the particular circumstances of the patient"* (Schei, 2006: 394). This definition has obvious parallels in nursing and allied professions.

The personal qualities referred to by Schei are strongly aligned with what Aristotle called virtues—character traits that strike a balance between undesirable extremes (such as courage, which lies between the vices of recklessness and cowardice). Another family physician with an interest in philosophy, Peter Toon, has challenged principle-based medical ethics (in which clinical practice is guided by a set of core principles such as beneficence, non-maleficence, autonomy and justice) and argued that above all else, doctors must develop their professional virtues through reflection and peer support (Toon, 1999). Good nursing practice has also been defined in terms of personal virtues (Bradshaw, 1999). The UK's professional body for doctors acknowledges the importance of virtues in the opening paragraph of its guidance "Good Medical Practice": *"Patients need good doctors. Good doctors make the care of their patients their first concern: they are competent, keep their knowledge and skills up to date, establish and maintain good relationships with patients and colleagues, are honest and trustworthy, and act with integrity"* (General Medical Council, 2012:1).

Whereas the objective dimension of clinical practice is typically tightly defined in terms of adherence to best evidence guidelines, the subjective dimension is something of a mystery (Heath, 1997)—depending as it does on a form of knowledge that is tacit, experiential and difficult to codify (Polanyi, 1958). The judgements made by virtuous, wise clinicians entail ethical and practical considerations not just about what to do in relation to the particular circumstances of *this* patient but also—and especially in a cash-limited healthcare system—how to balance the competing demands of advocacy (addressing the needs of the individual patient) and distributive justice (balancing this patient's needs or wants against the wider needs of the population in the context of limited resources). These considerations play out, for example, in relation to questions of whether to prescribe, whether to operate, whether to refer and so on (Heath, 1997).

Despite the exponential growth in medical knowledge and the availability of numerous algorithms and technologies for decision support, being ill is, above all else, a state of vulnerability and uncertainty about the future.

Critical scholars have voiced concerns that the essence of good clinical practice is being lost as society moves from a traditional era in which medicine and nursing were viewed as vocations, health care as a public good, and the sick patient as a vulnerable citizen who had a right to care (and to whom the clinician had a duty of care) to a new era of market values where medicine is a business, health care a transaction, and the sick patient a customer. In the latter era, informed choice by "empowered" patients is seen as the driving force for achieving excellence, since clinicians (and health services) that do not produce satisfaction will quickly go out of business. The doctor's role is defined either as seller of specialist services or as an information purveyor. It follows from these assumptions that a good clinical encounter is one in which the patient or their nominated advocate has been given sufficient balanced information to make a well-informed choice (Barry and Edgman-Levitan, 2012). The empowerment of the patient is assumed to exist, more or less, in a zero-sum relationship with the disempowerment of the doctor—with the caveat that many patients do not wish to be completely autonomous but seek shared decision-making.

But in the vocational model, patient empowerment and ethical practice are all defined differently. For one thing, it is illness itself, and not medical paternalism, that makes patients vulnerable (Schei, 2006). Doctors' specialist knowledge has symbolic significance; power is not so much seized by doctors as conferred by society (doctors symbolise hope, trust, agency and authority, making possible a powerful *therapeutic alliance* of reciprocal interpretation and projection [Balint, 1957]). This "cognitive institution" facilitates doctor-patient interaction and produces a *"legitimate hierarchy of domination and subordination, recognized by all participants"* (Schei, 2006: 397). In this hierarchy, patients are doubly vulnerable—because they opt (or are compelled) to rely on the doctor's skill and judgement in potentially life-threatening situations, and because they expose themselves to the potential for shame or loss of dignity as intimate secrets and body parts are revealed (with the risk of loss of face if this is met with ridicule, disbelief or indifference). The doctor's power is more "power to…" than "power over…," and hence its systematic removal may not be in the best interests of vulnerable patients.

(continued on next page)

The framing of the patient as rational chooser underpins numerous policy initiatives in healthcare—including what is referred to in the UK as the Expert Patient Programme (EPP) and in the US and Australia as the Stanford model of self-management of chronic disease (Lorig and Holman, 2003). Building on an extensive program of randomised controlled trials of self-efficacy training, such programs seek to train the person with chronic illness to monitor the parameters of their disease and make "healthy" life choices, thereby coping more effectively with their condition and preventing or deferring the onset of complications. But this approach is not without its critics:

> EPP valorises cognitive practices, focusing on improving self-efficacy and imparting general coping strategies, better breathing and healthy eating, improved communication and working with health care professionals. As such, its patient model resembles that of "Rational Man" [sic] privileging objective, logical and autonomous decision-making. In addition it is intended to inculcate an ideal typical late-modern patient: responsible, self-directed and managing her own health. (Pickard and Rogers, 2012: 2)

The flaw in this argument, suggest sociologists Sue Pickard and Ann Rogers, is that it is predicated on a mind-body dualism in which *knowing* one's illness is equated with converting one's inner bodily states to a set of abstracted, rational data items (such as blood sugar level or blood pressure)—hence knowing becomes "knowing about" rather than "experiencing." Each abstracted value is considered to map to a single disease and reflect a more or less generalisable bodily status (for example a blood pressure of 200/100 in one 50-year-old male would reflect a similar pathological state to the same blood pressure in another 50-year-old male). Furthermore, the individual is expected to follow standardised coping protocols to deal with fluctuations in these values (or prevent the fluctuations from happening).

The best treatment is not necessarily the one shown to be most efficacious in randomised controlled trials, but the one that fits a particular set of individual circumstances and aligns with the patient's preferences and priorities.

The good (or in UK terminology, expert) patient is defined as one with high levels of self-efficacy—that is, one who confidently and competently undertakes the monitoring and management of the particular physical and mental variables that are defined as constituting the disease. The role of the doctor or nurse in such situations is, as Schei suggests, one of information purveyor, providing key items of information needed for the individual to make those all-important rational choices about his or her disease.

Following the French philosopher Maurice Merleau-Ponty, Pickard and Rogers suggest that the expert patient is actually characterised by a very different form of knowing—the *existential* knowledge of the lived body. The challenge of living with chronic illness, and especially with multi-morbidity, is to integrate embodied self-awareness with the practical work of living with chronic illness. This work often involves navigating a host of physical and cultural challenges within the family, community, and healthcare system.

The Dutch philosopher Annemarie Mol has argued that decision-making (shared or otherwise) is a relatively minor aspect of the care of chronic illness. As health problems increasingly involve chronic, non-communicable diseases which require ongoing effort by both patients (self-management) and health professionals (periodic surveillance, management of exacerbations, and long-term support of disability and impairment), so the logic of choice (episodic, decision-focused, objective, predictable—as in a decision tree) becomes less relevant than the logic of care (continuous, relationship-focused, intersubjective, unpredictable). The logic of care, Mol suggests, includes the role of the doctor or nurse as witness and active listener—but it also includes the practicalities of care such as the effectiveness of medication in controlling symptoms, the accessibility of the clinician at times of need, and whether tools and technologies introduced with the aim of supporting the process of care turn out to be usable and useful in particular situations. In this framing, care has both a physical, material component *and* a socio-emotional one.

Despite the emergence of these promising new framings of the illness experience and the care relationship, medicine and health policy remain dominated by the logic of choice. Furthermore, underpinning the increasing colonisation of medical discourse by the "rational man" (metaphorically gendered, and referring variously to the doctor or the patient, depending on who is doing the decision-making) is the inexorable replacement of reason with rationality. As sociologist Andrew Sayer (drawing on various scholars including Aristotle, MacIntyre, and Nussbaum) has argued, rationality is distinguishable by its formal and instrumental character, its abstraction from concrete situations, and its focus on means rather than ends—for example, it is concerned with identifying the most efficient method of getting a job done but is not centrally engaged with the rightness of the job itself. In contrast, phronesis (practical reason) is characterised by its concern with the concrete and the particular; its practical, embodied and tacit character; its focus on ends rather than means (in particular, whether the ends are ethically justified); and its focus on people and relationships rather than objects (Sayer, 2011, see also Montgomery 2006).

> A reasonable person is someone who takes account of the specificities of the people they interact with, their particular capacities, needs and vulnerabilities, as well as other specificities of the situation. … When we talk of having "reasonable expectations" of people, we mean expectations that take into account their particular characteristics, constraints and resources, including their vulnerability and fallibility, and "reasonable behaviour" also suggests some degree of emotional sensitivity to others. Further, to be a reasonable person is to be able to imagine things from other people's standpoints—in other words, to be willing to take the standpoint of the other. … Hence to call someone "a reasonable person" in such contexts suggests an **ethical** judgement of them. (Sayer, 2011: 65)

Sayer's distinction between reasonableness and rationality is, perhaps, the difference between *caritas* and an overly narrow (though very often expressed) interpretation of *scientia.* It is surely time we reclaimed the notion of *caritas* and sought to theorise it further in relation to issues such as the increasingly common situation of the aging individual with multiple chronic conditions; the growing expectation that people will "self-manage" such conditions; and the need for doctors and nurses to support self-managing patients through interpersonal relationships and the reflexive use of symbolic power.

Despite the exponential growth in medical knowledge and the availability of numerous algorithms and technologies for decision support, being ill is, above all else, a state of vulnerability and uncertainty about the future. In Sayer's words, "A key characteristic of pain and suffering is that they are not merely states of being, but of frustrated becoming, or continuous yearning for relief and escape." Good doctoring is less about achieving equal distribution of power or enabling "choice" than it is about ensuring that doctors draw on their personal virtues (integrity, honesty, and so on) and socially conferred power to build a healing relationship and take practical action in the patient's best interests.

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Cognitive Enhancement:

Choosing to Know the Future and to Not Know the Past in Bioethics

Simon Outram, PhD

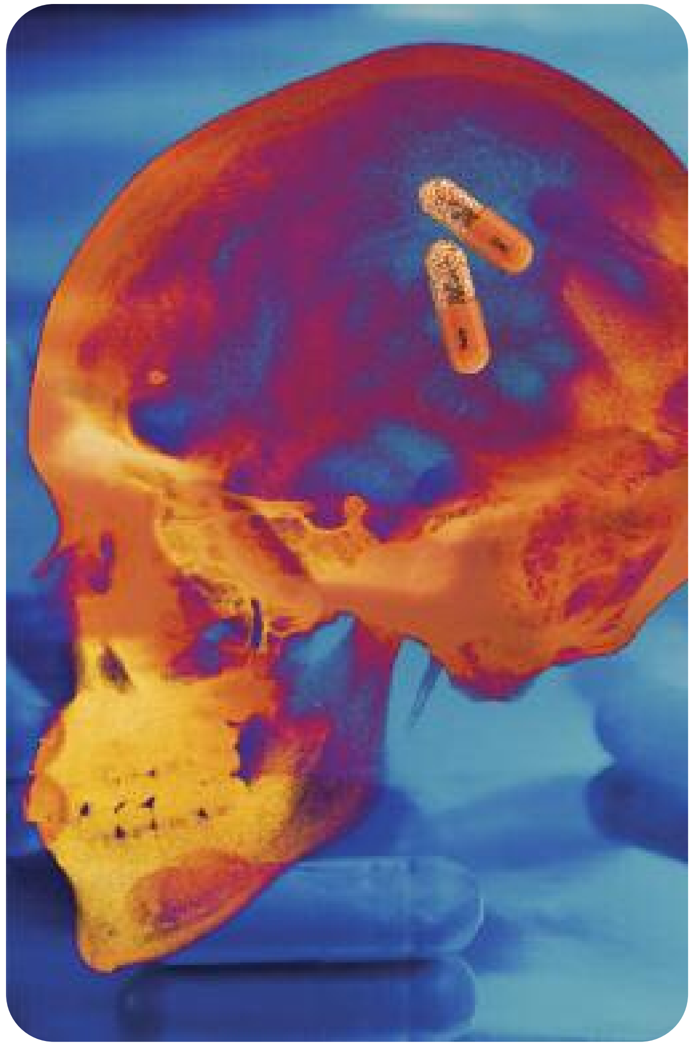
I have spent a great deal of time examining the topic of cognitive enhancement over the past two years, and as I have reviewed the landscape of the bioethics discussion, I have become less concerned with the ethical arguments presented for and against cognitive enhancement practices, and more concerned about why there is a discussion at all. Ethical arguments concerning cognitive enhancement are based upon a curious platform: *we know the future* but *do not know the present or the past.*

Defined at an abstract level, cognitive enhancement is the intention to increase the cognitive abilities of healthy individuals to above "normal." Being above normal could mean having an improved memory for names and faces or it could encompass the more nebulous objective of improving intelligence. The most ubiquitous method of achieving cognitive enhancement is education and the most ubiquitous external technologies of enhancement are pens and paper and personal computers. The most ubiquitous internal facilitator of cognitive enhancement is improved diet (especially if the normal state of the individual was a nutrition-poor diet from an early age). It is difficult to argue that these are not technologies of enhancement at least in some senses. However, it is the use of medical technologies—especially psychotropic drugs—that is under the academic microscope. This is especially the case in bioethics.

The drugs most often referred to in the ethical debates over cognitive enhancement are methylphenidate, modafinil, and mixed amphetamine salts (Adderall). The underlying premises upon which such debate stands are simple—the drugs work (or will work) and people use them (or will use them). I agree with all of these premises, but each of these premises also applies to coffee, and virtually nobody sees coffee drinking as a threat to society or way of transforming individuals into cognitive over-achievers. So, let us consider these premises again with respect to methylphenidate, modafinil, and mixed amphetamine salts. Do these psychostimulant drugs work? Yes (but…). The literature is growing and largely concludes that stimulant drugs are stimulants (!)—on a short-term basis, they encourage us to focus. There is no scientific evidence to suggest stimulant use and intelligence is correlated or causally connected and sociological data from students does not suggest higher grades. Do people use them? Again—Yes (but…). Stimulants have a long and continuing history, including a history of usage among students for exams. But the prevalence of use has been relatively stable for the past decade and is well below the use of marijuana, alcohol, and cigarettes. As for the future, who knows? But there is nothing to indicate the science of stimulant drugs is changing, or that (ab)use of stimulant medications is substantially rising.

Yet many participants in this discussion are choosing to know the future but not to know (or at least learn from) the past or present. I suggest this for two reasons: the first is an empirically-based argument concerning the efficacy of these drugs, and the second is a question of attributing meaning to enhancing activities. Empirically, in choosing to emphasise the potentiality for such drugs to enhance, many discussants have chosen not to know that there is only highly limited (or even no) evidence that such drugs are enhancers (as opposed to, or in addition to being, stimulants). Reviews of scientific data strongly indicate that methylphenidate has little or no effect on health in cognitive terms, modafinil is no better than coffee as an enhancer, and mixed amphetamine salts (Adderall) are simply another generation of amphetamine (which chemically they are!). If "enhancement" means more than mild stimulation (keeping you awake for the final hour in the office) it is difficult to find evidence that any form of enhancement is achievable through these drugs. Yet many scholars working to analyze the ethical implications of cognitive enhancement choose simply not to know this literature, or engage with it only as a caveat to argue precisely the opposite: that we should become fully engaged with the possibility that such drugs might work in the future and thus we need to become fully engaged with the ethical implications of a radically cognitively enhanced humanity.

While I am concerned that scientific and sociological evidence is used (if at all) solely as a caveat before launching into claims based upon knowing the future, I am equally concerned that on the tightrope of interpretation—between over-interpretation and under-interpretation—discussants have chosen to ascribe meanings to a range of drug uses that have little traction in the experiential world. When students take pills (today and in the past) before an exam, I suspect that they are not engaged in something that would qualify as a grander scheme to become more cognitively enhanced; they are attempting temporarily to concentrate for a specific purpose. When a conference presenter takes beta blockers (another drug referred to as an enhancer) to calm down before her lecture, she is using a chemical technology for an easily identifiable purpose, and that purpose is not becoming a more intelligent or cognitively superior person. If such actions are to be called cognitive enhancement, this is the prerogative of the describer of the event rather than the person taking the drug itself. Coffee drinking, calculator use, and stimulant (ab)use at university are daily occurrences. They have meaning, but to intimate that their current meanings (something as simple as "I want to stay awake longer") are irrelevant, temporary, or unsatisfactory requires more evidence than is provided. I think there is plenty of data about the present and the past to suggest these banal meanings will hold true for some time. Perhaps the most honest conclusion that we can reach about cognitive enhancement of the form that would really challenge us ethically is that people don't really cognitively enhance because they can't. Enhancement technologies that would really challenge us ethically don't exist in anything but an anecdotal manner, devoid of social meaning and practicality. I am not against asking questions about the future, but if we want to ask such questions, we should at least ground these questions in knowledge that we already have.



Recently, I was asked to present a paper on how bioethics has managed to transform the illicit use of stimulant drugs into a form of cognitive enhancement. I arrived with my standard array of arguments to bash the extreme speculators. However, after hearing the keynote presentations on politics and bioethics, I reviewed my thinking and reflected that perhaps I was doing a disservice to bioethicists engaged in this debate. It is not that discussants are transforming drug (ab)use into enhancement—it is that by choosing to know some things and not others they are making political choices. I am also making a political choice. I am proposing that we know the evidence points in one direction—a highly limited direction—and that the future trajectory of enhancement will likely be more of the same. Others will use the same evidence to claim the opposite. I would argue that both claims are political because they are meant to have consequences. It is to the credit of bioethics that it is willing to speculate upon unknown futures. But discussants should not hide behind claims that they are reflecting scientific possibilities. Discussants are actively engaged in trying to create futures, or at least trying to create concerns about the future, and in doing so they have actively chosen to not know about the past. These are political choices. My political choice is to embrace the "don't know" of cognitive enhancement, and I have two political messages. The first is a negative message: Don't believe the hype about cognitive enhancement! The second is a positive message: If we are to address the future of enhancement, academics would be better served by addressing the regulations and laws that govern access to such drugs as they exist and as they are derived. We do not need to look speculatively into the future to see that the laws most closely associated with cognitive enhancement are derived from the context of drug regulation and the control of medications. Stepping out of our current regulatory context and exploring what has happened to drug laws historically and analogously in sport would allow us to challenge and/or reaffirm the ethical basis of current regulations. This form of analysis could be highly productive and equally appropriate to the task of regulation, but does not require us to carry forward unsubstantiated assumptions about the efficacy and popularity of such enhancement drugs. From this position we could launch into the task of creating an ethical enhancement policy with our feet firmly on the ground.

Simon Outram is currently researching performance enhancement through the use of nutritional supplements in sport at the Institute of Sport Exercise and Active Living, Victoria University, Melbourne, Australia. The substance of the above article stems from research into cognitive enhancement carried out at Novel Tech Ethics, Dalhousie University, Canada. This research encompassed ethical discussion, sociological profiles of use, science evidence for enhancement, and the role of discussants in creating or reducing the market for such drugs. simon.outram@vu.edu.au

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CONFESSIONAL

RUMINATIONS ON

AN OCULAR CURE TESTIMONIAL

Brian Hurwitz, MD, FRCP, FRCGP

Gritty, sore, red eyes are an unlikely scenario for pondering whether meta-analysis can ever catch up with a clinical hunch. But this is the story of a hunch that arose from clinical experience and conflicted with evidence-based studies of how best to treat acute infections of the outer layer of the eyes—meta-analyses I co-authored—and of how I reacted when my clinical experience ran counter to a modern-day, scientific cure testimonial.

As a family physician in central London, I'd almost always treated people with acute infective conjunctivitis with antibiotic eye drops. But in the year 2000, two co-authors and I found the risk ratio (RR) of clinical benefits associated with an antibiotic to be 1.31 (95% CI 1.11 to 1.55) 2-5 days after starting treatment, and 1.27 (95% CI 0.92 to 1.74) 6-10 days afterwards—figures that emerged when we did the first systematic review of the literature with statistical pooling (meta-analysis) of data derived from randomised controlled trials.[1,2] The numbers look technical and sound noisy, but by tracing their role in the turns and twists of what happened I hope to show how deeply contextual they turned out to be.

The numbers in brackets appended to the second RR in our meta-analysis showed the alleviation of symptoms to be less demonstrable at 6-10 days than at 2-5 days. Its confidence interval (CI)—a measure of the precision of the estimate of the RR—dipped below 1.00 at its lower end, implying that the odds of benefit from treatment could well be equal to the odds of benefit from placebo (*no* treatment with antibiotic). Where the odds of benefit from treatment are the same as the odds from no treatment, the ratio of the risks (the RR) lies within an interval that includes 1, signalling no net gain for the average patient from treatment (see Table). This finding was matched by the high rate of spontaneous resolution we found: by the early time-point of follow-up, 64% of study patients given placebo eye drops no longer had symptoms, the condition having resolved spontaneously. So although our analysis came up with odds which indicated that by 2-5 days benefit had accrued from an antibiotic, less than a third of people on the therapy were likely actually to have benefitted from it; many, it was judged, would have improved spontaneously, either because the condition was self-limiting or because the inert solution of placebo eye drops also relieved symptoms.

As a casualty officer in the 1970s I'd been taught the customary UK practice of treating infective conjunctivitis with an antibiotic. Although viral conjunctivitis (the cause in about half the cases) does not respond to this sort of medication, an antibiotic aided recovery without harming people with the viral condition, so I adopted this approach in my own practice. I had seen it used to good effect in hospital clinics, and had co-authored a paper on how to diagnose and treat the condition at a time—as now—when laboratory analysis and culture of pathogens in conjunctival fluid took too long to assist clinicians in distinguishing bacterial from viral causes of the condition.[3]

Bacterial and viral causes of conjunctivitis result in a very similar clinical picture: sore, red, watery eyes, sometimes with discharge, blurred vision and swollen eyelids—unpleasant symptoms which some people find debilitating. Other than interest in estimating effectiveness of treatment, one of the concerns that drove this first systematic review was related to the safety of the ocular antibiotic most commonly used in the UK, which has since been found to be safe.[4] Another concern was a growing worry that prescribing antibiotics for conditions that may not be bacterial in origin increased the risk of creating antibiotic bacterial resistance. Since conjunctivitis was (and remains) very common—accounting for between 1-4% of all consultations in primary care[5]—it was important to estimate the effectiveness of antibiotic treatment.

Table: Relative risks (RR) for a beneficial outcome in 3 meta-analyses of the effectiveness of broad spectrum antibiotic treatment for acute infective conjunctivitis

Date	Type of Benefit	No. of Trials	No. of Patients	Early RR (95% CI) 2-5 days	Later RR (95% CI) 6-10 days	% Early Resolution (CI) on placebo (2-5 days)	% Late Resolution (CI) on placebo (6-10 days)
2001	Clinical	3	527	1.31 (1.11-1.55)	1.27 (0.92-1.74)	64 (57-71)	NA
	*Microbiological	3	527	1.71 (1.32-2.21)	1.71 (1.26-2.34)		
2006	Clinical	5	1034	1.24 (1.05-1.45)	1.11 (1.02-1.20)	65 (59-70)	72
	*Microbiological	5	1034	1.77 (1.23-2.54)	1.56 (1.17-2.09)		
2012	Clinical	11	3673	1.36 (1.15-1.61)	1.21 (1.10-1.33)	30 (27-35)	41 (38-43)
	*Microbiological	11	3673	1.55 (1.37-1.76)	1.37 (1.24-1.52)		

*Microbiological benefit refers to a significant reduction in the presence/concentration of bacterial pathogens in conjunctival fluid.

Five years after the first study we updated the review and meta-analysis with information gained from additional trials covering twice as many people as were included in the original study.[6,7] This second review confirmed the results of our first one: the RRs for clinical benefit in the second study turned out to be lower than those in our first study, and their CIs at early and late time-points almost touched 1.00 (see Table). As the Table shows, we identified benefit by the early time-point, but discounted its value because the benefit was hardly demonstrable only a few days later.

What wasn't included in these meta-analyses was my creeping sense of discomfort over the implications of the data, which were interpreted to mean that for the average patient "acute bacterial conjunctivitis is frequently a self-limiting condition" and that "topical antibiotics offer only marginal benefit in improving clinical outcomes"[7], a view which ran counter to my clinical impressions and beliefs. Vastly more often than not I'd found antibiotic eye drops to be an effective treatment, relief from eye symptoms frequently coming on within hours of starting medication. But, I said to myself, the particularities of one clinician's experience and inferences are precisely what evidence-based medicine (EBM) promises to transcend in marshalling and summating the results of controlled trials from far and wide. Having extracted and meta-analysed the best quality data and published them in the international Cochrane Library of "highest level medical evidence," we expected that in time the findings would supplant the cure testimonials of professionals like me, its conclusions becoming incorporated into texts that recommend only treatments of proven effectiveness.[8]

The trials included in our meta-analyses were not all the same in their design or undertaking; they differed in the patient inclusion and exclusion criteria adopted, the antibiotics used as treatments (sometimes ointment was used instead of drops), in the measures and timings of outcomes assessed, and in placebos used (the exact compositions were not always specified in trial reports). Overall, the differences suggested a degree of incomparability between the randomised trials that lessened the validity of our statistical pooling without vitiating it. And in the face of these conclusions, despite heterogeneity across the trials, I dutifully began withholding antibiotic eye drops from patients with infective conjunctivitis.

Woodcut from the Chinese Ming (C 14-17th) medical text, Michuan Yanke Quanshu, *a secretly transmitted compendium of ophthalmology, illustrating the condition known as infectious chiyan ("red-eye").*

Credit: Wellcome Library, London. L0038864

The first few people I did not treat seemed to suffer worse pain and discomfort for longer than those for whom I'd previously prescribed an antibiotic, and all—from memory four ("from memory" being a telling expression)—ended up coming back to me with persistent, troublesome symptoms. One person lost important time off work, and although I could not know for certain whether this represented a worse outcome for him than had he used an antibiotic (i.e. whether delayed recovery time was a consequence of a worse severity of infection or the result of a pathogen-host interaction that happened to be at the extreme end of the spectrum), I found myself confronted by a small series of worse patient outcomes associated with non-treatment. This situation persuaded me to discontinue the non-treatment approach in my own practice, and I quietly returned to prescribing antibiotic eye drops for patients with this condition.

I felt guilty about my change of heart: a meta-analysis has much greater power to detect relatively small treatment effects from controlled trials than an individual clinician making uncontrolled observations and inferences amongst the possibly unrepresentative group of people who happened to consult me over a short period of time. But what was I to do in the face of a clear (and a trained) sense that outcomes were worsening with a non-treatment policy, outcomes based on clinical impressions which in other situations I trusted?

As a co-author I felt especially uneasy; reverting to previous practice on the basis of a handful of vividly reported symptoms by patients whom I feared had suffered avoidable morbidity from an evidence-based policy exposed me to a charge of cleaving to customary (outdated) practice in the face of studies that had no axe to grind. A charge of hypocrisy could also be levelled at me. I was abandoning a peer-reviewed standard which I myself had helped create precisely in order to articulate the evidential basis for treatment—and I now found myself unable to take those conclusions to heart. In turning away from such "gold standard" recommendations was I turning away from my own scientific work?

In 2012 we published the third study of this question, an analysis based on eleven trials and five times the number

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of patients who had been included in the first study, and this data pointed to a different conclusion.[9] The 2012 study found higher odds of clinical benefit accruing at 2-5 days from an antibiotic, odds that were clearly maintained at 6-10 days and reflected, also, in increased odds of pathogen eradication from conjunctival fluid at both time points (with no CIs approaching 1.00). Our 2012 study is more powerful than the earlier ones and carries less chance of false positive and false negative findings. It concludes that “Early clinical and microbiological remission rates by day five are improved following administration of a topical broad-spectrum antibiotic, benefits that persist but are more modest at the later time-point of follow-up”* (see Table), findings clearly aligned with the previously questioned customary practice.[9]

The credence given to antibiotic effectiveness in the most recent meta-analysis stems partly from substantially lower spontaneous resolution rates: 30% at 2-5 days and 42% at 6-10 days versus 64% and 72% in the second meta-analysis, differences which imply that a significantly larger proportion of patients stand to benefit from antibiotics than had been identified by the earlier studies (see Table).

I am relieved that data have now emerged which support the action I took years ago, and that my practice is no longer based on flimsy and self-contradictory grounds. Instead of customary “irrational” practice and a small case series, my approach to this condition now has a footing in evidence-based studies. And it is reassuring that my non-standardised, uncontrolled, unblinded observations undertaken in the context of everyday practice, which generally rank so low in the epistemological hierarchy of modern medicine, did not on this occasion lead me too far astray; that—for the time being—I needn’t struggle to reconcile the actions I took then with tensions generated by identifying myself with stereotypes of old fashioned clinician and modern-day investigator. But such relief is probably temporary. Each successive meta-analysis has been based on the extraction of data from larger numbers of trials and observations, a sure sign that although these data now point firmly in the direction of benefit, investigators will continue to question the place of antibiotic therapy for this condition. In the minds of clinical scientists—and the ethics review committees that scrutinize their research proposals—the question of an effective treatment policy for this condition remains unsettled. Though often discussed as if definitive, the implications of meta-analysis are rarely so. Perhaps these sorts of studies are best viewed as provisional summaries, estimates of effects on average patients that punctuate series of investigations extending into the future.

Current National Health Service (NHS) advice to people with symptoms of conjunctivitis confidently reports that: “antibiotics are not usually prescribed for infective conjunctivitis because they make little difference to your recovery and there is a very low risk of complications for untreated conjunctivitis. However, if the infection is particularly severe or it has lasted for more than two weeks, you may be prescribed antibiotics. Some schools or playgroups may insist that a child is treated with antibiotics before they can return, although this is rarely necessary.”[10] This advice is grounded in the first and second (but not yet the third) meta-analysis, and takes particular notice of a study that recommended a delayed treatment strategy for conjunctivitis. This study found antibiotic drops reduced the duration of eye symptoms by a day-and-a-half and suggested a policy of no treatment, together with a prescription for antibiotics to be taken if symptoms persist in 3-days’ time, the rationale being that symptoms which are going to resolve spontaneously in three days’ time should be allowed to do so (a policy that trades early potential benefit from treatment against the desirability of not over-prescribing antibiotics). This policy may have led to a 15% fall in ocular antibiotic prescriptions in the UK, although the number of such prescriptions still amounts to some 2 million annually, a figure that calls into question the NHS claim that antibiotics “are not usually prescribed” for conjunctivitis. Ironically, since ocular antibiotics have now become available for purchase over the counter, total ocular antibiotic usage in the UK has been rising.[12]

> We should have grappled then with the undecidability of the evidence we’d found concerning low odds of benefit from treatment.

The nub of the issue I faced with my patients could have arisen from individual patient outliers going unrecognised by recommendations based on group averages; odds of benefit that over time (in more trials with more patients) shifted in numerical value towards levels that suggest an antibiotic benefits the average patient. “Outliers are not liars” (Andrew Herxheimer, personal communication 2012), rather they signal the complexity and heterogeneity of medical truth. Figures which tell of an effect in a certain reference class cannot be a compulsory guide to how to treat outlying members of that class, for whom it’s quite likely (and comprehensible) that the average effect may be different.

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* Despite demonstrable odds of clinical and microbiological benefit in the third meta-analysis and the lower spontaneous resolution rates than in the earlier studies, our 2012 study offered a twofold “staged” advice: “Given the self-limiting nature of conjunctivitis, operating a wait and see policy to see if symptoms/infection spontaneously resolve appears reasonable. It is also a ppropriate to consider use of antibiotic eye drops as these increase the speed of resolution of symptoms associated with acute bacterial conjunctivitis.”[9, 11]

Did I turn away from the EBM advice because I thought *all* my patients with this condition must be outliers? Although an attractive explanation, I could only resort to it if the group of four who fared worse from no treatment was representative of my practice population. Something about the *seriality* of four patients in a row who appeared to have suffered worse outcomes without treatment, the absence of expected variability of outcome in even a small series I’d met with personally, led me to doubt that the odds of benefit from treatment equalled (or almost equalled) the odds of benefit from no treatment. Another way of putting this is that I turned away from the EBM stance because I suspected the implicit, unarticulated evidence on which customary practice had been based combined with my own (flimsy) evidence on the negative effects of withholding antibiotics pointed to an effective treatment: antibiotic eye drops. Currently, the weight of evidence happens to support my intuition of years ago. But in retrospect, the fragility of the advice of earlier meta-analyses (reflected perhaps in its language, which clearly hedges) should have caused the authors and reviewers—especially me—more pause. We should have grappled then with the undecidability of the evidence we’d found concerning low odds of benefit from treatment. Data are always incomplete and of mixed quality, but years ago I should have had the courage of my data-light convictions and published my change of heart, a change arising not only from intuition but from the one-at-a-time testimonies of patients talking about their symptoms and my own observations of how they responded (or not) to treatment (or not).[13]

To mention intuition in a paper prompted by Kathryn Montgomery’s work might seem risqué in view of her critical elucidation in *How Doctors Think* of the misuse of this notion at the hands of clinicians[14], but I venture it here to denote an unanalysed suspicion, arising in the midst of clinical practice, which I acted on then without fully articulating the basis of my change of prescribing policy. Twenty years ago, Kathryn persuasively argued that the practice of medicine is not itself a science although it derives much of its method, logic and theory from the physical and biological sciences.[15] In *Doctors’ Stories,* an intellectually penetrating, path-breaking work, she argued that medicine is much better understood to be “a rational, science-using, interlevel, interpretive activity undertaken for the care of a sick person.” This formulation embraces sensory, “soft,” wordy, and highly variegated non-averaged information, which in my practice I had construed as evidence—evidence that came up against the findings and stance of EBM recommendations, and held its ground.

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Not Just a River: Denial as a Strategic Integration of Knowing and Not-Knowing

Lisa Sanders, MD

"Doc, I'm just fine," the man said; it's what he always said. But it was no truer that day than it was any of the other times he'd said it. Mr. Williams* wasn't fine; he was sick as sick can be. He was 64 and a patient in my internal medicine practice for just over a year. He hadn't been to a doctor for decades, and only started seeing me after his untreated diabetes and high blood pressure landed him in the hospital and just about killed him. By the time I sent him home, both of these chronic diseases were pretty well controlled.

When I saw him a couple of weeks later, he looked well. He joked with the office staff and flirted with the medical assistant. But when I checked his blood pressure and blood sugar, they were sky high. I was shocked. At first I chalked it up to his eating a different diet at home and maybe problems taking his many medications—some he had to take two or even three times a day. So, over the next few months I changed his doses and simplified his regimen; I worked on his diet and urged him to exercise; I reached out to his wife and children to support him in his efforts. Nothing seemed to help.

Six months after being discharged from the hospital Mr. Williams was on whopping doses of insulin and a medicine chest of blood pressure drugs, and though he said he felt just fine, both his diabetes and his blood pressure were still wildly out of control. What was I doing wrong here? I told him he needed a specialist, because somehow I wasn't able to help him.

"Doc," he said brightly, "it ain't you; it's me. I'm not taking your stupid medicines." I stared at him—not knowing what to say. "Look, I'm not sick. I don't feel sick. I'll take your medicines when I feel like they can do me some good." He gave me his most charming smile as if to tell me it was nothing personal. "Till then," he added, "you can just keep 'em."

I saw him several more times that year. At each visit I talked about his diabetes and high blood pressure and the risk he was running of ending up in the hospital or even in the ground. He'd just smile and tell me that if he was really sick, he'd know it.

Now, lots of people don't take their medications. Studies show that up to half of us do not take our medications as prescribed. About 12% don't take their meds at all.[1] Why not? There may be as many reasons as there are patients: Money, naturally, is a common reason. And side effects—real or simply worried about. And there is the difficulty of managing the organizational skills needed to take the meds and get them refilled.

Doctors routinely overestimate how well their patients take their medications. Why? In part because they don't tell us. Even when asked. If, as TV's grumpy internist Gregory House maintains, everybody lies, I suspect a goodly number of those lies have to do with medications.

Now that my patient had confessed, I tried to imagine what the barriers were for him. Was it money? No, he told me. His insurance paid for them. I simplified his medicines as much as I could and gave him a 90 day supply to reduce the hassle of refills and his wife was a picture of organization. Was it side effects, I asked repeatedly. Nope, he told me, I just don't need 'em.

And then, I didn't see him for a while. When I called to follow up he told me he didn't think it made any sense for a healthy guy to go to the doctor.

A few years later, I heard he was in the hospital. He'd had a massive stroke and had lost the use of his right arm and leg as well as his ability to speak. A few months later, his wife pushed him down the hall to my exam room in a wheelchair. He smiled, but it was only half a smile; the other half of his face remained immobile. He waved with his good hand, but he couldn't say hello. He was doing fine, his wife told me. He took his medicines every day now, she reported. I nodded and tried to smile back.

Early in my intern year I cared for another patient in the hospital who, like Mr. Williams, was almost dying because of this same, inexplicable reluctance to take the medications he needed to control his chronic diseases. After we'd admitted the patient to the hospital, my resident, a cherub-cheeked doctor named Klar, leaned close to me and said quietly, "Yeah, it's not just a river." I looked up, completely baffled. Denial—the Nile—he explained. It's not just a river.

In the years since I have come to realize this silly pun might be on to something: denial is like a river, one that runs between the shores of knowing and not-knowing. How patients with chronic and potentially life-threatening diseases —like high blood pressure, diabetes, heart disease, or cancer—negotiate that river predicts how well, and often how long, they will live with those diseases.

Sigmund Freud described denial as a defense mechanism that allows the ego to avoid the anxiety of a threatening situation by negating its reality. It was, he thought, a tool that allows us to modulate how much we know and don't know at any given moment.[2] Painful or distressing thoughts and emotions can be kept at bay, providing the ego with time to become strong enough to deal with a changed situation.[3] A couple of decades later Elizabeth Kubler-Ross fit denial into her 5-stage paradigm of how individuals cope with grief—starting out with denial, moving through anger, bargaining and depression, and finally arriving at acceptance. The trajectory from denial to acceptance is frequently viewed as a necessary path the sick and dying must tread to have a healthy attitude toward their new and unexpected fate. The assumption is that people need to move from a state of denial, where, like Mr. Williams, they refuse to acknowledge the reality of their diseased state, to a state of acceptance, where recognition of their illness allows them to do what needs to be done.

But recent experiences have suggested to me that denial is more than simply an embrace of not-knowing, a flat-out rejection of reality. Instead denial contains a dynamic relationship between knowing and not-knowing. Even those who seem to completely refuse to acknowledge their illness will often reveal that they know it's there. Mr. Williams came to see me for years even when he wouldn't accept his illness or take his medication. Knowing—on some level—that he was sick made going to the doctor make sense. And this navigation between knowing and not-knowing can be a successful strategy for tolerating the intolerable.

Recently a good friend, Doug, was given a diagnosis of glioblastoma multiform—a rapidly progressive, almost universally fatal type of brain tumor. Every time I saw him, after he'd heard the news and after the surgery, after the radiation and the chemotherapy, he was as he had always been—upbeat and filled with plans about what he was going to do next, or as he put it, after "all this."

His wife was supportive, but worried. She confided to me one night, "I think Doug is in denial." He was still hard at work though not at the ridiculous pace he'd kept before "all this." The couple ran a small company together and Doug's illness was the first issue they hadn't been able to come to an agreement on in many years. His short-term memory had been affected by his tumor and its treatment and, try as he might, Doug couldn't completely hide that. She got calls from friends, colleagues, and customers asking about him. Yet Doug refused to tell anyone about his diagnosis, his wife told me. It's nobody's business, he insisted, even though it was clear to many who knew him that he was not himself.

Navigation between knowing and not-knowing can be a successful strategy for tolerating the intolerable.

Yet Doug's unwillingness to embrace the full implications of his diagnosis did not interfere with his ability to participate in his treatment. He took his medications; he saw his doctors. He went to radiation therapy and chemotherapy. But when not forced to deal with his disease, he seemed to store it somewhere at the back of his mind so that he could get on with the very real issues of living and working without the pressure of that knowledge weighing him down.

That his mind did not work as well as it did once—he had problems with short term memory and often performed the same task several times without recalling he had done it before—made his work less consistent. He did not let that stop him. When confronted with it, he denied that as well. His attitude was like that expressed by the dying man in the 1975 film, *Monty Python and the Holy Grail*, who, when thrown onto the wagons collecting those who died from the Plague, shouts out, "I'm not dead yet"—insisting that, come what may, right now, at this moment, he is alive and that is all that matters.

Before Doug, my understanding of denial was largely shaped by my experiences with Mr. Williams and patients like him—patients who are unable to find

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The patient's name has been changed.

terms on which they could agree with their new circumstances. When patients come to the doctor's office, when they are in the hospital, they are embracing, or at least tolerating, the fact of illness and participating in the activities required to manage that disease. They cannot be in denial, since here they are, dealing with it. And based on this moment of interaction, I —and I suspect many of my colleagues —assume that this knowledge is present in their lives outside the office as well. Mr. Williams's moment of confession ("Doc, it ain't you it's me") permitted me a glimpse into a more varied and real version of a patient's movement between knowing, which brought him to my office, and not knowing, which allowed him to stop taking his medications outside that medical environment.

Doug's insistent refusal to allow dying to interfere with his living beyond what was absolutely required of him gave me a much greater understanding of the complex titration of truth—of knowing and not-knowing—that allows people with chronic and life-threatening diseases to manage. Watching my friend Doug made me rethink denial and what it means to those with life-threatening illness, an insight I would not have gotten if I had seen him as a patient. I suspect Doug's doctors consider him a perfect patient and could not imagine the extent of his denial outside their treatment rooms.

Rather than viewing denial as a static, negative state, perhaps it would be more accurate to think of it as a boat sailing a river between a condition of knowing and that of not-knowing; one in which individuals might shift between the knowledge of what lies ahead and carefully constructed ignorance of those same possibilities. The healthiest movement, when confronted with the existential threat posed by a chronic and potentially life-threatening disease, may not be a straight route from not-knowing to knowing, from denial to acceptance, but instead one that meanders between the two so that one simultaneously knows and doesn't know, and which is dominant can shift based on what is needed at that moment. It is how an individual navigates that river of denial that determines if the journey is beneficial or not, not the river itself.

This careful commute describes our own everyday knowledge of the inevitability of death. Most of us are masters of knowing we must die and yet ignoring it—or at least setting it aside so we can get some work done. The late Christopher Hitchens recognized this near universal denial of our ends as he approached his own. After being diagnosed with stage 4 esophageal cancer, Hitchens knew his was a terminal disease: "There is no stage 5," Hitchens famously informed us in a much-quoted TV interview. In his slender volume *Mortality*,[4] written in the last months of his life, he acknowledges his own denial: "Always prided myself on my reasoning faculty and stoic materialism," he tells us, "…[y]et consciously and regularly acted as if this was not true, or as if an exception would be made in my case" (86). Earlier in describing these contradictions he tells us, "[T]his is no more than what a healthy person has to do in slower motion. It is our common fate" (72).

When faced with a potentially life threatening illness, denial seems a natural response. In one study, 47% of patients receiving chemotherapy for a diagnosed cancer agreed with the statement "I don't really believe that I have cancer."[5] In another study 26% of patients in hospice care had some degree of denial in the weeks and months before an imminent death. And yet the assumption in medicine is that denial will have a very bad impact on outcome. Certainly it can. There are plenty of studies showing that denial can allow those who are sick to refuse beneficial therapies. And other studies have shown a higher rate of depression among those who are found to be in denial. Indeed, it's hard for physicians to see or even imagine denial other than the kind that results in the poor adherence to a medical regimen that usually brings these patients to medical attention.

And yet my experience with Doug convinced me that denial isn't always destructive. A number of recent studies show that patient attitude—denial versus acceptance—can positively affect prognosis or outcome. A few studies suggest that denial, along with "a fighting spirit," may predict a better prognosis among patients with cancers that have not metastasized. Unrealistically optimistic attitudes have been shown to allow many patients to cope with the stress of their illness more effectively.

And acceptance—long considered the hallmark of a healthy approach to illness and death—doesn't always improve outcome. In several studies performed over the past 30 years, acceptance has been associated with poorer outcomes in populations of women with breast cancer and other malignancies, as well as populations with other progressive diseases such as HIV.[6]

The paradigm of denial-versus-acceptance is really a debate on the benefits of knowing versus not-knowing in the face of chronic or life-threatening illness. Acceptance is framed as a full embrace of that knowledge, but I suggest that it is not an all-or-nothing proposition. Denial should be recognized as a more fluid negotiation between the two shores of knowing and not-knowing. I suspect that most doctors recognize—at least eventually —the denial of patients like my own Mr. Williams. But I suspect that the Dougs of the world may remain hidden from medical attention. And because they remain hidden, the potential utility of well-managed denial has been underestimated.

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WHEN THE PATIENT KNOWS WHAT THE DOCTOR DOES NOT (YET) KNOW

Kimberly R. Myers, PhD and Julie Mack, MD

Kimberly

Since I was in my twenties I knew I would be diagnosed with breast cancer. With no family history, no risk factors, no suspicious test results, and therefore no credible reason to anticipate this diagnosis, I nevertheless knew intuitively that I would get breast cancer. And I did.

As a teacher and scholar of medical humanities, I am usually thinking in some way about the nuances of patient-doctor relationships and communication. This professional awareness complicates my identity as a patient, especially because most of my physicians are also my colleagues and sometimes even close personal friends. The inevitable blurring of professional and personal boundaries is difficult for colleagues, whether patient or physician, particularly in the context of a serious diagnosis. What follows is an analytical reflection on the interplay of intuitive and empirical knowing, embedded in the stories of this patient and the radiologist who diagnosed her.

Physicians frequently advise patients, "Listen to your own body; you know it better than anyone." In the actual clinical relationship, though, tensions exist between a patient's intuitive knowledge and a physician's empirical knowledge, and these tensions have very real ramifications. For instance, a central goal of communication in the clinic is that the patient be a "good historian," reporting any and all information that might be relevant to her care. To facilitate this, the physician must cultivate an atmosphere of trust that enables the patient to divulge information that, while potentially embarrassing or awkward, could be critical to whole-person care.

Because of my premonition of breast cancer, over the years my perspective had progressed from sensible concern about breast health, to apprehensiveness about check-ups, to outright fright about anything to do with breast disease. I shuddered at scientific updates on epidemiology that I might encounter in professional journals; personal narratives by patients, or stories in film or television (frequent, given my work with pathographies and my general literature-and-medicine focus); reports on emerging diagnostic or treatment modalities featured on nightly news broadcasts… and *certainly* the imperative for breast self-exams. Indeed, I finally decided that the burden of stress I experienced once a

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month at the time of my self-exam outweighed the benefit of potentially discovering a mass early, so I carefully orchestrated annual mammograms and gynecology visits so they would fall roughly six months apart. At least, I reasoned, something or someone (other than me) would be monitoring my body twice a year "before anything might have time to get out of control."

Upon my move from teaching literature in a university to teaching in a college of medicine known for its humanities program, I figured it might be wise to confide in my PCP just how dramatically this darkening intuition—and the snowballing anxiety that ensued—was affecting my life. This plan seemed decidedly auspicious since my newly-minted internist was a graduate of a program with a strong emphasis on medical humanities and biomedical ethics, and I was one of her first post-residency patients. And after all, over the course of five or six visits in three years, she had always been attentive to the concrete information I had given her. Like any other well-trained physician, she presumably felt empowered to do something, to act. When I first reported persistent pain in my left breast, for instance, she ordered a diagnostic mammogram. It was normal. So was the next one, a year later. So were the three exams she performed on me, for that matter. But the pain persisted, and my sense of foreboding intensified.

"So what does this mean?" I constantly tried to divine, to analyze. Am I imagining things? Am I *creating* things? Is this well-founded intuition or is it some sort of perverse self-fulfilling prophecy? Is it an example of what my well-meaning but woefully oblivious walking buddy said, "You attract what you fear"? (Well, that's great.) When medical tests don't validate strong intuition, at what point —and to what extent—does the intuitive patient begin to doubt herself and her perception of her symptoms, especially if her intuition has proved remarkably accurate throughout her life? This is doubly confounding for highly analytical, self-reflective people, and poses an even greater quandary for those who work in health care settings and repeatedly hear frustration and exasperation regarding patients who appear to be malingering.

Not wanting to become a "problem patient" whose symptoms are dismissed by a doctor, I tried to dismiss my own symptoms and make an uneasy peace with constant cognitive dissonance. "This breast pain must just be a fluke," I repeat in my head, day by day, moment by moment. "Nothing is palpable and nothing is visible on the films." From this vantage point—theoretically mirroring that of any frustrated physician who has dutifully followed up with all the right tests—a vigilant patient's wisdom in "listening to her own body" slowly morphs into shame that she "imagines things." Intuition has become hypochondria, she fears.

Given that patients want and need to be taken seriously, the stakes are high when discussing non-empirical phenomena—even higher, perhaps, when one's doctor is also a colleague. What if the patient is dismissed as neurotic by the very person left to care for her? Fearing that talking about her intuition might affect her physician's opinion of and behavior toward her, to what extent should the patient script a calculated discussion in order to minimize the possibility of dismissiveness or even abandonment? Surely these uncertainties themselves contribute to stress, which is implicated as a contributing factor in a host of disease processes, including breast cancer.

Entangled in this web of concerns, I furtively googled the most clinically detached description I could think of to describe what I was experiencing: "health anxiety." To my surprise, this search yielded links to the DSM, where I found this condition a "legitimate" diagnosis. Armed with official diagnostic language other than the alternative—and more culturally freighted—term "hypochondriasis," I could come clean with my internist. Perhaps she would respect my dispassionate, straightforward tone as an indication of healthy self-awareness. I would report this information as matter-of-factly as I would present a patient on morning rounds if I were a physician. I had my approach.

Initially, my internist seemed sympathetic to my situation and supported my plan to have mammograms in January and breast exams with her in July. I was gratified that I had withheld the darkest manifestations of my anxiety—she need not know every macabre detail—so that I still had some credibility in the clinical setting. That is, not everything I reported would be disregarded as merely "imagination," a word some use interchangeably with "intuition." This was July, and as usual she found nothing during the physical exam. Six months of respite before the onslaught of anxiety surrounding the next imaging test—which was, again, normal. When I saw her in clinic the following July, she asked why I was there, seemingly forgetting our six-months-from-mammogram-to-office-visit plan. When I reminded her, she seemed reluctant to follow through with the breast physical exam and said that in the future she would perform only the tests that were medically indicated, not every test I simply thought I should have. Her tone was condescending and paternalistic, as if she refused to cater to the whims of a hypochondriac and that we needed a little rational rationing to remind us what was what—and who was who. I felt shamed by her.

Assumptions were made and trust was shattered. No longer having an ally and now doubly closeted in my apprehensiveness, I walked into the breast imaging center the following January with an even greater sense of dread than usual. Getting ready that morning, a horde of scenarios careened through my mind: "The next time I make this bed, my whole world could be in shambles"; "When I look into this bathroom mirror again, I could see Cancer Patient"; "This might be the last time I enjoy a cup of coffee without worrying about a tumor in my breast." It went on and on. The morning was cold and rainy. Not a good omen, I thought.

Julie

I wandered down the hallway and looked for the technologist whom I would be working with on my next case. My eyes drifted to the diagnostic waiting room where a face sat perched above a crouched body, shrouded in one of our gowns. The eyes were familiar but the expression was not; the last time I had seen her, I read energetic curiosity in her face. Today her fear confused me.

I walked into the room and spoke her name as a question: "Kimberly?" She looked up at me, her frame looking fragile in a gown, not the woman I remembered. There were others in the waiting room, so I motioned her to the hallway. I asked if she was okay, immediately presuming she was "called back" due to a possible abnormality on her screening test, or that she was there to have a new symptom investigated.

She said, "No, I wasn't called back."

My eyes must have registered confusion. She was in our diagnostic waiting room.

"The left-breast pain I had a couple of years ago has come back." She wrapped her gown closer and apologized. "I'm sorry, this is just a hard test for me. It always has been. I haven't been sleeping."

She does not want to wait for results by phone or by letter. She wants to know now.

I touch her arm, hoping to comfort. "Would you like me to read your study?" For a moment, I see relief in her face and she smiles. "Yes, would you?"

I walk back down the hall and I am unsettled by her fear. The last time I had seen her, she wasn't a patient. She was a professor of literature, energetic, my husband's mentor. Last time she wore a bright jacket, her shoulders broad, and her arms open and waving. The eyes I remembered radiated enthusiasm as she presided over the awards ceremony for submissions to the literary magazine she edited.

I ask one of the technologists to bring the films on Dr. Myers to me when the study is complete. I re-enter the dark reading room and continue on with my daily work. A little later, the technologist returns. The 4-view standard images are ready.

My eyes register heterogeneously dense breasts, a mix of greys and whites. A three-dimensional structure flattened into two dimensions. A border catches my eye. "Probably overlap," I tell the technologist. "Can you just take another spot there?" I know this will produce more fear in my patient, but I plan to give her the good news when it is all done. I walk down the hall to let her know that I want an additional image. Overlap of tissue can produce all sorts of odd forms, and another picture will sort it out. She is alone this time in the waiting room, and I am standing. I briefly review what I need. I expect nervousness. The response is panic.

"What did you find? Do you see something?"

Her eyes are wide, her shoulders small. I sit down next to her and begin a longer explanation. "You have dense breast tissue; overlap of tissue can produce odd shadows on the film. I'm just being careful. If the additional views are normal, we'll be done."

"What if they're not normal? What does that mean?"

Her eyes are wider, her mouth open. I attempt again to calm her. The technologist moves in and takes her into the exam room for the additional views.

The spot view comes back, and I stare at the area. The technologist waits. Was I letting my nerves get the better of me? Had my patient's fear become mine? I walk down the hall for a second opinion from a trusted colleague.

"I know her. She's nervous. Am I overcalling this?"

"Yes."

I pause briefly and contemplate stopping the exam without pursuing additional imaging. But doing nothing feels worse than pursuing the hint of a shadow on the mammogram. I confess to the technologist, "I'm doing this as much to calm my nerves as hers. Humor me and let's put her in ultrasound."

I will feel more confident if I can clear her breast by sonography. But first I have to talk to her again. I take a breath and walk down the hall.

(continued on next page)

I look again into her fear, and try to explain what an ultrasound can do—that we often see cysts in patients with dense breast tissue.

"Does a cyst indicate malignancy?"

"No, a cyst is just fluid within the normal spectrum of breast physiology."

"Does that predispose me to cancer?"

I try again to comfort, explaining that sonography is just another way to look at the breast. I do not discuss the data on dense breast tissue and elevated cancer risk. I haven't calmed her down, and her anxiety level disorients me. I explain that we have to contact her physician, as we can't move ahead with additional testing until we have a written order. It will require that she wait. Would she like to come back later? It was a silly question.

I walk by the waiting room several more times on my way to see other patients. It is not typical for me to pay attention to this room, but today I do.

She is reading.

She is tapping.

She is staring.

I call her doctor directly for the order, bypassing the front desk. I can't wait any longer.

The technologist moves her into the ultrasound room and types her data into the machine.

I enter the dark room and see she is quiet, staring at the ceiling, her agitation diminished. I am calm, comfortable in this room with a probe in my hand. I move her gown down and drape a towel over her breast, leaving a portion uncovered. I squirt warm gel on the probe, and place it on her skin. Scattered islands of white glandular tissue separated by bands of grey fatty breast tissue fill the screen, and I am relieved. Her breast tissue is easy to scan, smooth transitions between white and grey, with only inconsistent shadowing from the supporting ligaments. I move the probe down and slightly toward the middle, and an aberration appears on the screen. It is against her chest wall, a small dark splotch, interrupting the normal contour of the tissue. I move the probe away, turn it slightly, and move it back to the area. The splotch persists. I quietly speak to the technologist, "Mark this radial 9:00, 2 cm from the nipple." I make an initial measurement. My patient has turned her gaze from the ceiling. She is staring directly at me, and now her fear is familiar; it makes sense to me, something I witness in most emotionally healthy patients when I find something that needs biopsy.

"What is it? Is it a cyst?"

I lift the probe off her skin.

"No, it is not a cyst."

I pause, and phrase my next sentence carefully.

"Kimberly, I don't like the way it looks."

I realize I haven't used many words before she grasps the import of what is going on. More words about what it looks like will not help her understand it anymore than she already does.

Her face contorts, her eyes squeeze tight, and she breathes too fast.

I put the probe down, pause, and touch her arm again. I begin the next discussion, a transition to another test. It is the biopsy procedure I later learn she has long been expecting.

Reflections

Julie

I have replayed that day in my mind many times, wondering why I moved to sonography in this patient on that day. I had sought a second opinion from a trusted colleague, but even before she had given her opinion that a sonogram was probably not warranted, I had decided to pursue the additional test. On another day, the same findings might not have crossed my threshold of "abnormal" and I, too, would have passed the study as negative. After all, there's no certainty when examining shadows on films for patterns of disease, especially in patients with dense breasts. This is a truth that all radiologists understand and must learn to live with. Nonetheless, on that day, I could not even come to a relative certainty. Sensing that something was off-kilter in Kimberly—even though I could not pinpoint it precisely—caused my mirror neurons to fire early and repeatedly, and my adrenaline to rise. Perhaps this synergistic connection and subsequent physiological response enhanced my perception of the subtle finding on the film. Perhaps I just feared missing an important finding. Whatever the process, Kimberly and I now shared the same fear. Something was wrong; something sinister eluded detection.

I sat with Kimberly a few days later as she was waiting for her MRI exam. She looked tired now, but she was calm. We talked a bit about what had happened that day. Remarkably, despite the circumstances of a new cancer diagnosis, she expressed gratitude. She told me she was glad that I had been there that day and that I had moved ahead with additional testing. I too was thankful. Had I not seen Kimberly in the waiting room and connected with her on a subconscious level, I might have seen only dense tissue on her mammogram and missed the early finding that could make a difference in her long-term prognosis.

Kimberly

At some later point in my treatment, Julie asked me whether there was any period of time between her discovering the mass and my receiving the pathology results that I had convinced myself it wasn't cancer. No—not only because Julie is a well-trained, gifted radiologist with years of experience, but also because I immediately recognized this finding as the thing I had known was coming all along. And while I was devastated by the findings, in a curious way it was also something of a relief to finally receive the diagnosis. Perhaps it was because there was no more relentless cognitive dissonance. Or perhaps it was a vindication of sorts that wiped away the awkwardness and distress I had come to feel about knowing something doctors did not yet know.

That said, here's the rub: the mass was in my right breast, not the left where I had felt pain. Although breast cancer is rarely painful, and breast pain is common, my recurring left-breast pain is what warranted a "diagnostic" mammogram (as opposed to a "screening" mammogram); and being in the diagnostic room is what led Julie to see me. In a way, intuition had found a voice considered legitimate in the clinical setting; pain had done its work by triggering the cascade of events that unfolded. What's more, after the initial stages of diagnosis, the pestilential anxiety that had hounded me for decades receded into near quietness.

Though this essay most directly addresses the interplay of intuitive and empirical knowing, it also touches on another way of knowing: knowing people in multiple ways. For example, in the thick of trying to process my diagnosis and the white-hot shock that followed from it, I was also very concerned about Julie. I kept thinking how utterly awful this liminal position must be for her: to have to give this news to a friend, to be saddled with the weight of her professional responsibilities in an otherwise personal relationship. In short, I felt remorse for having (inadvertently, to be sure) put a colleague and friend in this difficult position.

Indeed, writing this essay was itself difficult because it took us out of carefully prescribed professional roles and into murky territory of multiple and simultaneous ways of knowing each other. But it was also wonderfully cathartic and illuminating; in exploring the acts of speaking and listening in a clinical setting we discovered that we recalled the same events, but we remembered the language quite differently. Because the word "cancer" has long been taboo for me when I have been in the position of patient in a clinic, I'm certain that I would never have asked Julie outright if "this is cancer." I would have used all sorts of circumlocutions and euphemisms, as are generally reflected in this essay. But when Julie recounted her memory of that day, she remembered my initial response to her request for extra mammographic views as "Do I have cancer?" It was what I was thinking, and it was what she "heard," but I'm sure those words were never spoken.

The richness of these insights leads us to believe that similar collaboration between patients and physicians would be quite fruitful, fostering better communication and deeper trust, and therefore ultimately more effective clinical relationships. We also believe that, based on the experience we describe here, clinicians should respect intuition—their own and their patients'—even when empirical tests contradict it. Doing so just might save someone's life.

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The non-science of medicine

Abraham Schwab, PhD

Imagine you're playing Russian roulette and you're handed a revolver with bullets in two of the six chambers. You can remove one bullet for a fee. How much would you pay?

Now imagine you're playing Russian roulette and you're handed a gun with a bullet in one of the six chambers. You can remove this bullet for a fee. How much would you pay?

This example comes from a text I use in my classes (Bazerman and Moore, 2009), and my students consistently are willing to pay more in the latter instance than in the former. From a perfectly rational economic view, similar improvements in chances of survival should warrant similar willingness to pay. Accordingly, the higher value placed on removing the bullet in the second example is irrational: removal of one bullet in the first case and removal of the only bullet in the second case are identical—both improve the chances of surviving by 16⅔%. Why, then, are my students willing to pay more in the second scenario? And why is it that I completely understand and want to endorse their willingness to do so?

Humans will act irrationally to achieve certainty. Rational economics aside, *lowering* the chance of death by a bullet just does not feel as valuable as *removing* that chance entirely. We want certainty, and we'll do a great deal to get it. This predictable irrationality was first illustrated some 30 years ago, when Slovic, Fischhoff and Lichtenstein (1982) showed that certainty skews our judgments about the relative value of equivalent changes in probability. More recently, in *How Doctors Think* Kathryn Montgomery deftly described how certainty pervades the medical context. In an illustration of its cultural import, she describes how physicians can slip into a pose of certainty (189-190) and how the ritualized interactions that cloak physician-patient interactions with certainty can be carried out even when both patient and physician know it is a sham (199-200). Patients want particularized certainty (what will happen to *me?*) and physicians want it too (what's the best treatment for *this* patient?).

Science provides an important backdrop for medical practice by organizing rigorous protocols, analyzing clinical data, and producing conclusions with confidence. But even these measures are applied unevenly; uncertainty lingers at the edges of this narrowly defined domain. It is left to patients, physicians, and other members of the health care team to respond to the lingering uncertainty. I am calling such responses the non-science of medicine, and in what follows I describe two prominent types.

The first response is pseudocertainty. When certainty is utterly beyond the scope of what science can study, when claims can be neither confirmed nor denied through numbers, tests, or measurements, physicians may still treat the question as though there is certainty about the answer. Take the two-sided question at the edge of life: is it alive? (Or conversely, is it dead?) Medicine provides answers to these two questions down to the minute. At the beginning of life, medical practitioners provide certification of birth, and at the end of life, medical practitioners express no less certainty, declaring a time of death. But one does not need to be particularly well informed about the issues surrounding the beginning and end of life to know that this certificate and this declaration are more artifice than science.

This is true even in the most acute of circumstances —take Aleksandar Hemon's story about his infant daughter Isabel, her brain tumor, and the experiences of his family. He and his wife are in the hospital when Isabel requires CPR to remain alive. The medical team works, at the parents' request, to keep their baby alive; when her heart stops beating yet again, the team goes to work. Then, after excruciating minutes pass:

> Isabel's heart starts beating again. The gray-haired doctor turns to me and says, "Twelve minutes," and I cannot comprehend what he is saying. But then I realize: what he is saying is that Isabel was clinically dead for twelve minutes. Then her heart stops beating again, a young resident is halfheartedly compressing her chest, waiting for us to tell her to stop. We tell her to stop. She stops.

When did Isabel die? When the resident stopped compressing her chest? When her heart stopped before the resident started compressing her chest? During the time she had been clinically dead for 12 minutes? At some earlier moment during her arrest when her body would never again be able to sustain itself (whenever that moment was)? No certain answer here, yet the certificate includes a definite time of death.

Our willingness to accept certainty at the edges of life despite the ambiguity may be the result of our willingness to settle for pseudocertainty. By pseudocertainty, I refer to the appearance of certainty that even the most cursory reflection uncovers to be a lack of certainty. The classic method for illustrating our preference for pseudocertainty is to ask individuals about insurance: when offered two insurance contracts, one that would cover half of an event that occurs 20% of the time, or one that covers 100% of an event that occurs 10% of the time but will cover nothing of another event that happens 10% of the time, respondents typically pick the latter even though the policies are economically equivalent (Slovic, Lichtenstein, & Fischhoff, 1982). Evidence of yearning for even pseudocertainty is found throughout medical practice. Patients and physicians find comfort in a definitive diagnosis, although every diagnosis's certainty is mitigated by a disease's uncertain expression (or by the fact that it's a "syndrome" —which often translates to "we don't know what it is, but these symptoms seem to show up together for a lot of people"). Yet pseudocertainty is preferable to none at all, so when it's plausible to do so, we pretend to be certain.

The second response to uncertainty occurs in cases when we cannot even pretend to have certainty, when even pseudocertainty is out of reach. In these cases, patients and physicians respond by treating the uncertainty as utterly profound. The common refrain, "statistics don't tell us what will happen to *this* patient," is true in a banal sense. Of course no scientific inquiry will tell us what will happen to *this* patient—since we can't tell the future, we don't know what will happen. Philosopher David Hume made this point 250 years ago. Nonetheless, in medical practice the point is taken too far: because statistics can't tells us everything, they're treated as though they don't tell us anything. This is obviously a mistake. If the best available treatment carries a 75% chance of success, the patient wants to treat the disease, the patient has no significant concerns about the side effects, and there is no better treatment available, the data tells the patient exactly what to do: begin the treatment.

Perhaps this overreaction to uncertainty is actually a kind of transference: patients confronted with a 75% chance of success and a chance of serious side effects aren't sure that the treatment is worth it. They can't decide, so they blame "the science" for not providing complete certainty. But the blame could just as easily fall on those patients, for being unable to make a judgment that involves undeniable uncertainty. We're just not used to making judgments while explicitly accounting for probabilities. For example, ask the average person if a Starbucks coffee is worth three bucks, and she will give you her personal value judgment easily. This is a pretty clear quid pro quo. If she says yes, then ask if she'd be willing to pay $1.50 for a 50% chance of a cup of coffee and watch her struggle.

Our limited ability to incorporate probabilities can corrupt the judgment of health care providers too. I was fortunate to be able to attend prenatal appointments during my partner's first pregnancy, and at one appointment she was asked if she would like testing for Fragile X and a number of other genetic abnormalities. She was then provided with the sensitivity and specificity rates of the tests, but that is all. I was incredulous. Knowing the sensitivity and specificity rates of a test like this is important, but the significance of a positive or negative result is also determined by the base rate of the genetic abnormality. Without that information, no one could possibly make a good judgment. This anecdotal evidence is buttressed by studies that show the limited ability of physicians to accurately decipher the meaning of sensitivity, specificity, and base rates for a positive mammogram (Hoffrage and Gigerenzer, 1998).

Patients, physicians, and other medical practitioners may be responding to the uncertainty of medical science by employing pseudocertainty or treating undeniable uncertainty as utterly profound because they are not in a position to make sense of probabilistic data. If they were more precisely informed, or better skilled at making sense of uncertainty, they would make better decisions.

But aiming at more precise information or more successful strategies assumes that there is some meaningful, scientific way to approach uncertainty. This is what I believe: there are causal mechanisms that we can more accurately theorize that will lead to better-calibrated predictions, more narrowly focused treatments, and more clearly identified outcomes. In other cases, where predictions remain incomplete, we can study features of human judgment to devise strategies that improve our decisions under conditions of uncertainty.

The primary basis for these beliefs is the amazing success of medical research (and science more generally) at manipulating the human body, and of cognitive psychology at understanding and nudging human behavior. The problem is that the evidence in favor of my beliefs is also the evidence for an incompatible alternative view. In this view, elements of our universe are imbued with an uncertainty that science cannot overcome. No matter how sophisticated and rigorously applied the methods of scientific inquiry may be, parts of reality will elude them. This position plays into the notion that the best kind of human life requires a certain kind of faith in the *je ne sais quoi* of human judgment. It allows the individual to "trust their gut" and to "follow their nose" because some things simply cannot be counted, measured, or rigorously analyzed. Human judgment is no less reliable than the structures of science. The seduction of the position is obvious for physicians and other medical professionals—their judgment will always be needed, their clinical skill is special. As Kathryn Montgomery puts it, "Neither science nor art, [clinical judgment] is an intellectual capacity carefully cultivated through the rigors of a long apprenticeship spent dealing with radical uncertainty" (53). In a reality imbued with an irreducible uncertainty, the practice of medicine requires the ineffable qualities of human judgment.

Proponents of this view could point to the same set of amazing successes that I use to support my view and ask, "But if it's all predictable and understandable, why haven't we done even better?" I don't have an answer for that question, but I continue to believe that we can improve our predictions and our understanding through scientific rigor. Of course, this belief may simply reflect my preference for certainty, or at least something that looks like it.

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Diagnosis–

A Tool for Rational Action?

A Critical View from Family Medicine

Kirsti Malterud, MD, PhD

"All diagnoses are provisional formulae designed for action."[1]

Henry Cohen, professor of radiology at the University of Liverpool, said this in his Skinner lecture in 1942.[1] Cohen's reflections about medical diagnoses may still be considered provocative within what Kathryn Montgomery describes in *How Doctors Think* as a "rational, science-using practice that idealizes a simplified, old-fashioned vision of science."[2] But Cohen's ideas about diagnosis are a useful point of departure for exploring medical epistemology with the fluidity of clinical knowledge in mind. For the family practitioner, an adequate question is often more useful than a correct answer, and appropriate action could actually be more significant than a diagnosis.

The limitations of diagnosis for medical problem-solving

Cohen contrasts two diagnostic strategies in medical history: Within *Hippocratic medicine,* the physician pursues the complete account of a particular patient to understand the balance between destructive and reparative processes and recognize resources which can reinforce repair by all available means. Within *Platonic medicine,* the physician pursues the disease as an ontological entity—a solid fact representing the actual pathology—in order to attribute the appropriate diagnostic label. This clinical mode is comparable to what Allan B. Chinen, professor of psychiatry, called "the representational mode of understanding."[3] Here, the physician aims for treatment and prognosis, identifying the name of the disease by revealing the structural abnormality.

The Platonic idea of diagnosis as the core symbol of clinical knowledge is mistaken. More than thirty years of experience as a family physician has convinced me that diagnosis in this sense of the word will only now and then signify the clinical knowledge needed for successful medical management. There are useful diagnoses—when a strep throat infection is diagnosed, penicillin proves to be the drug of choice and the patient is cured within a short time. And sometimes an ontological diagnosis is essential—knowing that the black spot signifies a malignant melanoma leads to urgent and necessary surgery, while a benign mole requires very different management. But a clear and clean linearity between clinical phenomena, the names we can give them, and a subsequent rational treatment is the atypical exception rather than the norm in clinical medicine.

The practitioner must therefore establish clinical knowledge beyond a Platonic disease diagnosis to understand what is wrong and what can be done. The practitioner who regards clinical knowledge as a pile of stable facts circumscribed by diagnoses abandons the complexity of medical problems. Montgomery describes diagnosis as a plot summary of a socially constructed pathophysiological sequence of events.[2] Hence, a broad range of perceptive and interpretative skills are needed to reach a useful verdict.

Clinical knowledge comprises a fascinating combination of instant, individualized evidence on the spot and group-based evidence from research, all within a timeline where knowledge is fluid and sensuous, and at the same time solid and factual.[4] The practitioner arrives at the individual encounter with an initial capital of basic medical knowledge from biomedicine, epidemiology, social and human sciences, and experiential knowledge. This preconception kit of knowledge is a necessary, but not sufficient, source for developing the fresh clinical evidence needed to elaborate the most adequate hypothesis in this particular case.[5]

Family physicians know that frequently occurring and recognizable compound symptom patterns which do not fit into established diagnostic labels may nevertheless be managed. A patient who suffers pain, fatigue, and depression receives different vague diagnoses from different physicians, but is still available for action strategies leading to change or coping. On the other hand, even established medical diagnoses will not always offer a tool for action—a patient who is precisely and repeatedly diagnosed with vaginal candidiasis might find that medication prescribed according to evidence-based guidelines has only a short-term effect. As a result, practitioners' quest for clear-cut answers in the format of a diagnosis may become a blind alley where more sensible understanding and strategies become ignored.

Epistemological circumstances in family medicine

Family medicine is a privileged context for exploration of medical epistemology, the knowledge about medical knowledge. In most Western societies, primary care is the main doorway for patients with undifferentiated symptoms and complaints. Some of these conditions resolve without further intervention, some will need simple or more complex management, while some remain in spite of appropriate action. The family physician takes medical responsibility for a majority of the population by investigation, follow-up, or as the gatekeeper of referral to specialist care.

For medical problem-solving, the family physician refers to a preexisting and evolving base of knowledge, while at the same time performing knowing as action under considerable uncertainty. The practitioner interprets the dynamic signs in the natural context of the patient's lifeworld, a body of knowledge which is far from stable.[6] Altogether these aspects constitute clinical knowledge, molded by circumstance, tradition, and interpretation. The context of family medicine demonstrates the shortcomings of traditional biomedical epistemology for understanding and managing common clinical problems. Although linear causation might satisfy medicine's positivist ideal, it is not quite the pillar of clinical method it might seem, says Montgomery.[2] The professional norm that objective signs are supposed to confirm subjective symptoms and thereby reveal monocausal disease processes falls apart in the sea of medical complexities encountered by the family physician.

To know the cause of disease is to have control.[2] During my years as a family physician I learnt step-by-step to appreciate and cope with what I henceforth will call the *fluidity* of clinical knowledge. As a novice, I felt puzzled by the mismatch of what I learnt in medical school and the medical problems I was expected to solve.[7] Gradually, I realized that it takes some specific skills to navigate in these blurry medical waters without getting seasick.[6] The basic yet significant competence is to transcend apparent incommensurabilities through advanced interpretive practice. Dichotomous thinking is dangerous because it encourages the practitioner to choose one alternative and dismiss the other. Instead, family physicians must be ready to merge paradoxes and opposing perspectives instead of perpetuating devastating dichotomies. Here are five of the most persistent oppositions which collectively demonstrate that dichotomies are epistemological pitfalls in clinical medicine.

1. The *narrative* structure of medical knowledge is gaining increasing recognition.[8] Yet, an ongoing simultaneous attention to *biomedical* processes should never be neglected.[6-7] A confined psychosocial perspective is not an adequate answer to the question of how people's lifeworld contributes to health and disease. Listening closely to the patient's story and his or her description of symptom perception is crucial to the physician's ability to ask additional questions, develop the most adequate hypotheses, and investigate their hypotheses by further investigation and tests.[9] Test results, however, are only interesting if they can support or refute a first-class clinical question. This is the reason I have been doing research on "Key Questions"—how an elaborated speech act can make a difference in

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clinical practice, using knowledge about the patient's problem definition, causal understanding, coping experiences, expectations about management, and self-assessed health resources as the foundations for rational hypotheses about what is wrong and what can be done.[10]

2. Another enduring dichotomy to be transcended is the question of whether a condition is *physical* or *psychological.* Theoretical perspectives from semiotics and cybernetics offer adequate models for understanding complex relationships between body, mind and surroundings, regarding living creatures as semiotic actors, molecular processes as mediating systems of signs, and information as connecting biological life and ecological surroundings.[11-12] German internists Uexküll & Wesiack brought these points of view together in their comprehensive theory about human medicine.[13] Modern psychoneuroimmunology has presented convincing empirical evidence about how body and mind are closely knit together by mutually interactive circuits which amplify and perpetuate the processes.[14-15] Conditions that for decades have been regarded as medically unexplained disorders, such as chronic fatigue syndrome or irritable bowel syndrome, are no longer mysteries or fancy, but fascinating demonstrations of the complexity of health and disease.[16] For more traditional medical conditions which appear explained to the medical doctor, such as diabetes or cancer, the body-mind merge becomes increasingly important. Questions about how body and mind are related therefore seem more adequate than whether this is the case.

3. Among the undifferentiated symptom patterns encountered by the family physician, the most common things occur *most commonly.* Symptoms are interpreted according to their probability. Montgomery discusses the probability challenges represented by the old medical maxim: "When you hear hoofbeats, don't think zebras."[17] Clinical epidemiology is among the important tools employed by the family physician when knowledge is developed by practical reasoning. The impact of signs and findings are ultimately dependent on pre-test and post-test probabilities. Nevertheless, exceptions representing the *low probabilities* occur among patients in family medicine. The subtle skill of focusing on commonalities while never forgetting conditions which hardly ever happen is an essential requirement for family medicine epistemology. The physician's guard of thinking twice must be low when something does not fit neatly, although the symptoms at first glance appeared to be among the trivial and well-known. This is why the complex cases often deserve an additional question instead of jumping to premature conclusions. Yet, referring again to Cohen, "We physicians are often confronted with a situation in which we have to give a provisional verdict on the admittedly inadequate available evidence. We must act."[1]

> For medical problem-solving, the family physician refers to a preexisting and evolving base of knowledge, while at the same time performing knowing as action under considerable uncertainty.

4. Another domain of oppositions is represented by *the temporal axis of family medicine.* While regular patients become familiar to the physician over years and generations, some patients are healthy passers-by who only attend for minor complaints. The impact of the patient-physician relationship is very different for these two groups, in both the sophisticated knowledge base as well as the emotional connections. Recognizing the early signs of hypothyroidism is simpler with a person you have known for a while. The lifelong acquaintance with a patient adds to the family physician's knowledge base, although it sometimes blurs the medical gaze with positive or negative stereotypes.[18] The epistemological challenge of health problems ranging from intermittent and trivial symptoms which fade away without any intervention and the burden of chronic and serious rheumatic disease or critical heart conditions requires exquisite priority skills, for the physician to decide upon an appropriate path for clinical management. The level of adequate action is also related to time, with a considerable proportion of conditions revealing their nature over a course of days, weeks, or months.[19] For the family physician, the question of urgency may be more important than the medical name of the problems—how long can I responsibly wait and see what happens?

5. Finally, the *complexity* and multimorbidity of medical problems in primary care, as compared to the Platonic ideal of disease as *entities that are easy to grasp,* create epistemological challenges in family medicine. While medical school still teaches medical knowledge as separate phenomena which can be structurally identified, isolated, and dealt with, the family physician must be prepared to encounter patients who simultaneously suffer from arthritis, heart failure, diabetes, and dementia. Overlapping symptoms may blur the diagnostic workout, and treatment is not simple since the expected side-effects of one medication make the other condition worse. This complexity cannot be covered by even the most elaborate flow-charts. Yet, evidence-based decisions must be taken. The acquaintance with particulars required to carefully adapt documented knowledge about diagnosis and treatment to the individual case is no argument to dismiss evidence-based knowledge, actually rather the opposite.[2, 5] Asking the adequate question about which aspects should be taken into account to achieve the best balance seems more important than finding the answer of whether group-based knowledge can be applied or not.

The significance of diagnosis beyond labeling

There is a gap between diagnosis conceptualization in medical theory compared to clinical practice. A diagnosis —the name of the patient's complaints —is no more than a label, although the pathologist would be dissatisfied if the diagnostic label did not imply a clearly defined etiology and pathology.[20] Within the representational mode of medical understanding,[3] diagnosis is supposed to explain the origin of the symptoms and thereby provide a platform for rational treatment and prognosis.[21] But consultations (at least in family medicine) frequently include diagnostic reasoning with no clear-cut answer.[19] The clinical scene does not always immediately present a diagnosis with the capacity to explain illness.[22] Furthermore, patients with the same diagnosis differ unpredictably.[2] The fluidity of clinical knowledge is evident in these epistemological circumstances.

Although scientific and technological advances refine clinical problems and provide solutions, physicians still work in situations of inescapable uncertainty.[2] This is one of the essential features of the fluidity of clinical knowledge, valid also for conditions which gradually present with a classical disease diagnosis. Yet family physicians have realized that the art of medicine is the ability to be effective with scientifically inadequate data, and that the solution of the patient's problem can often be achieved despite the impossibility of reaching an established medical diagnosis.[23] The uncertainty demands that the physician is able to put up with provisional conclusions.

Research from family medicine confirms that the diagnostic process is a fundamentally narrative practice, drawing first and foremost on the patient's story, taking the appropriate steps to exclude serious disease, then establishing rational shortcuts towards conclusions leading to action.[19-20, 23] The British family physician D. L. Crombie claimed that the establishment of a diagnosis is only one link in a chain which begins when the patient presents his problem.[20] Diagnosis is an interpretive negotiation of particular signs and symptoms and their development over time.[2] In consultations without a clear-cut diagnosis, family physicians staged their conclusions on a different level than traditional disease diagnoses. Instead, they categorized complaints as: 1) nothing dangerous, but it might look like… 2) testing by treating, and 3) tracking potential danger.[19] These conclusions evoked very different modes of further action. My hypothesis is that these strategies for development of clinical knowledge are not confined to medically unexplained disorders or to the context of family medicine, but constitute the foundation of clinical practice in general.

Medical diagnoses have different functions beyond indicating a pathway to treatment and prognosis. Among women with fibromyalgia, an initial response of relief was common when a diagnosis was finally reached.[22] For some, the diagnosis legitimized the symptoms as a disease; others felt better to suffer from fibromyalgia than more serious conditions. Nevertheless, sadness and despair emerged when they discovered limitations in treatment options, respect, and understanding. The process of adapting to this diagnosis can be lonely and strenuous.[22] A diagnosis may be significant when it provides the road to relief, understanding, or legitimization of problems. Naming is an important step in the process of creating meaning for persons who find themselves increasingly disabled by a chronic condition.[22] It may become a challenge for the physician to tolerate the uncertainty of a diagnostic concept such as fibromyalgia while supporting the individual patient by using the name of the disorder to create meaning in a life with chronic illness.

I have argued that diagnosis in the Platonic sense represents limited tools for action, considering the fluidity of clinical knowledge. Still, I am not ready to dismiss diagnosis from rational problem-solving in medicine. Tools for synthesis and categorization of clinical knowledge are definitely needed, but they should be transformed according to the epistemological context in which they are used.

Pragmatic development of relevant hypotheses

The representational mode of medicine has serious shortcomings, looking for the structural pathology of a distinct disease in the epistemological circumstances of complexity and multi-morbidity. The clinician needs to develop complementary diagnostic strategies for medical problem-solving, and that requires pragmatic approaches beyond identifying a name. Again, however, these agendas should not be considered dichotomous, but as complementary missions. Let us shift attention from answers to questions and from stable facts to dynamic function. If diagnosis is supposed to be a tool for action, we must also consider which kinds of action are available and relevant —or rather: which classes or phenomena a diagnosis should circumscribe in order to be useful.

In everyday language, "pragmatic" denotes practical solutions, drawn from more or less problematic compromises. This kind of practical solution is typical of the strategies demonstrated by family medicine research.[20, 23] A more formal application of this concept, *pragmatic philosophy,* is also useful as a framework to understand the role of diagnostic action within the fluidity of clinical knowledge. Theorists like Charles Sanders Peirce take human experience as a foundation for knowledge, focusing the consequences of the experience as the essential benefit of knowledge.[24] Along the same lines, Steinar Kvale discusses the significance of *pragmatic validity,* which refers to the relevance and utility value of interpretations and findings.[25] A pragmatic approach is needed for diagnosis to become a tool for rational action.

A fundamental mission in the diagnostic strategies of family physicians evaluating patients without a clear-cut medical diagnosis is to exclude or track potentially dangerous conditions, and to find out enough to decide what to do further on.[19] The practitioner does not always need to know the name of a disease to act (and watchful waiting is also a

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mode of action). Neither would there always be a need to act. Clinical knowledge, categorized as pragmatic diagnoses, will function as a guide to action and to determining an appropriate level of emergency. Appraisal of how serious and urgent the patient's condition is, based on a range of clues, will determine rational management, with "referral to hospital" or "wait and see" as pragmatic diagnoses.

The plot of the medical detective story includes more than the name of the perpetrator causing the danger.[2, 8] Encountering the fluidity of clinical knowledge, the practitioner needs strategies beyond hypothetico-deductive logics, where the problem is solved when the hypothesis is confirmed or refuted. Semioticians Sebeok & Sebeok discuss the problem-solving demonstrated by the famous detective Sherlock Holmes as compared to clinical practice, applying perspectives from philosophical pragmatism.[12] Peirce's logic of abduction is a mode of inference different from deduction or induction, necessary to develop an adequate hypothesis or pose a question leading to useful consequences.[24]

In the novel *A Case of Identity,* Sherlock Holmes enlightens his assistant Dr. Watson: "You did not know where to look, and so you missed all that was important. I can never bring you to realize the importance of sleeves, the suggestiveness of thumb nails, or the great issues that may hang from a boot lace."[26] Tacit knowing is an essential aspect of such processes.[2] The practitioner must learn to appreciate the capacity of sniffing his or her way by subliminal clues of perception and interpretation to a powerful question or the most relevant hypothesis, which can then be pursued. Clinical knowledge is not only fluid, it's sensuous, calling for more than rational logic to be understood and interpreted.[6] The taste of an elegant diagnostic hypothesis about what can be done may contribute to the daily joy of the seasoned practitioner.

Uncertainty, evidence, and reflexivity

Development of everyday clinical knowledge diverges in many regards from the search for knowledge in medical research. While the former is individualized, transient, and requires no scientific procedures for falsification or defense, the latter is more stable, available for evaluation and implementation in a generalized context. Clinical knowledge is constructed for immediate application, and is seldom validated regarding its transferability towards broader populations.

Yet the two types of knowledge construction are intimately interwoven in dialectic interplay.[4, 27] External clinical evidence from randomized trials and meta-analyses can inform, but never replace, individual clinical expertise in evidence-based health care.[28] The practitioner must catch up with the best available evidence to make the necessary decisions, and is often confronted with a situation where a provisional verdict on the admittedly inadequate available evidence is necessary.[1] Montgomery reminds us that medicine will never know everything for every case. The knowledge physicians have will not always translate into effective action, and beyond the search for accurate predictors, uncertainty remains.[2] What in hindsight may appear obvious may at the moment of action be much more blurred. Advanced gambling skills are needed, merging probabilistic competence and a psychological capacity to act under uncertainty.[4]

Drew Leder, trained in phenomenology as well as medicine, suggested that flaws in modern medicine arise from its refusal of a reflective self-understanding. Seeking to escape all interpretative subjectivity, medicine has threatened to expunge its primary subject—the living, experiencing patient, he says. Leder argues that clinical medicine can best be understood as an enterprise involved with the interpretation of the "text" of the ill person: clinical signs and symptoms are read to ferret out their meaning, the underlying disease.[29]

In this role, interacting with the patient and translating the available signs to evidence, the practitioner is a co-constructor of the fluid clinical knowledge, not a neutral observer. Postmodern epistemology disputes the widely held medical belief of "a view from nowhere."[30] Donna Haraway asserts that the perspective of the observer is always limited and determines what can be seen, hence knowledge is always partial and situated.[31] This does not mean that relativity rules with no general conclusions to be drawn, but implies that objectivity can be achieved only by revealing the positions and perspectives of the knower.

Considering clinical knowledge as situated explains why the medical gaze is not equally attentive to all evidence.[21] Signs referring to a chosen perspective are given priority, while others are neglected. For example, visual cues are ranked higher than auditive cues by the medical culture.[32-33] Gendered assumptions about patients which influence doctors' interpretation of medical symptoms and their diagnoses and management are well documented. This may be one reason women's health problems are often regarded as medically unexplained, beyond a diagnostic label: the physician will only be able to recognize and decode patterns which are already imprinted in the medical knowledge base—an andronormative domain where male standards until recently have been universal.[21, 34] But even recognition of well established medical diagnoses, such as the typical rash of zoster, requires that the symptom pattern is known by the physician in advance.

Medicine is also a moral enterprise, where the causes and consequences of evidence are value-laden, with a potential emotional and social impact on the individuals involved.[35] Moral knowing is therefore the essence of the clinical method.[2] Philosopher Arne Johan Vetlesen examines preconditions for moral performance in the individual subject:[36] To identify a situation as carrying moral significance, a person needs the basic emotional faculty of empathy, while indifference and distance jeopardize morality. Vetlesen summarizes moral performance as constituted through perception, judgment, and action, merging the emotional and cognitive faculties of the person. Moral perception is necessary to recognize the other as a moral addressee, as someone who will be affected by my moral performance.

The clinical encounter is constitutive of medicine. The specific knowledge generated in this encounter deserves status as medical evidence, and the validity of clinical knowledge deserves appraisal. If medicine persistently discards clinical knowledge from the realm of valid evidence, clinical practice will be isolated from scientific knowledge and medicine will lose its credibility as a scientifically based professional activity.[4] Reflexivity implies having a self-conscious account of the production of knowledge as it is being produced.[37] How, then, can reflective appraisal of the reading of clinical signs be elaborated into strategies for evidence based practice?

Exploring the social construction of clinical knowledge, while recognizing the fluidity within this field, we should acknowledge the situatedness of the physician as well as the pragmatic validity of the evolving knowledge. Internist William M. Zinn points to the significance of self-awareness in the doctor as the key to utilizing emotional reactions to improve the doctor-patient relationship.[38] These presumptions reveal important components for the construction of clinical knowledge.[4]

Epistemological marginality?

Elaborating philosopher of science Thomas S. Kuhn's theories, professor of family medicine Ian R. McWhinney demonstrates the assumption of the existing medical paradigm: that there are such entities as diseases, and the subsequent agenda of normal medical science is to describe and establish causes for these entities.[32] He states that a change of paradigm will occur when normal science encounters anomalies, casting doubt on the fit between the paradigm and nature.

In this article, my conceptual review of diagnosis has exposed a substantial epistemological misfit between the rigor of medical science and the fluidity of clinical knowledge. In order to identify, categorize, and solve problems in the context of complexity and uncertainty, the practitioner needs advanced skills beyond those provided by normal medical science. Above, I have put some of these forward. They add to McWhinney's presentation of anomalies revealed by family medicine, such as his first one: "Many people who are ill do not have diseases which can be classified according to our conventional taxonomy."[32] Some may say the frontier view of the family physician is a marginal and distorted anomaly compared to hospital medicine, or that the complexities and uncertainties of family medicine are deviant exceptions for the clinician compared to an epistemological context that's generally stable and predictable. I strongly disagree. Instead, my arguments above imply that our conceptions of epistemological marginality should be completely turned around, acknowledging the fluidity of clinical knowledge as completely normal.

> My conceptual review of diagnosis has exposed a substantial epistemological misfit between the rigor of medical science and the fluidity of clinical knowledge. In order to identify, categorize, and solve problems in the context of complexity and uncertainty, the practitioner needs advanced skills beyond those provided by normal medical science.

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Case Narrative and Objectivity, Chickens and Comics: My Story about Kathryn Montgomery

Susan Squier, PhD

In late June of 1997 the patient experienced a painful ovarian torsion caused by an ovarian mass. She underwent a hysterectomy-oophorectomy that left her weak and bewildered by her new body. I was the patient, and during those weeks of surgical recovery as I exchanged emails with my surgeon, I described to her the book I was then writing. *Liminal Lives,* I hoped, would explore "how the narrative of a human life is being drastically replotted (reshaped, revised) in the twentieth-century, with the help of beings marginal to the human: animals, embryos, fetuses." Scholar, know thyself. My own life had suddenly been revised, I didn't feel like its author, and I had no idea how the story would go.

By the third week of July, I joined Kathryn Montgomery, her co-leaders, and nine or so other scholars, health care professionals, lawyers, and artists for a seminar at Northwestern's medical school on "Case Narrative and the Construction of Objectivity."[1] Still feeling somewhat physically vulnerable, I was greatly cheered by the email I received from Kathryn: "When will you arrive? Could I meet you? You're not sposed to haul much, I suspect. Don't be shy. I WANT YOU HERE!" She did indeed meet me at the airport, taking over my wheelie bag and sheltering my unstable midsection from the strain of pulling a suitcase through the airport. That image sticks in my mind: me, fresh from the disorientation and pain of surgery and the boredom of recuperation, and Kathryn Montgomery, indomitable, encouraging, inspiring, pulling my baggage behind her as she shepherded me into this new and unknown phase of my life.

The conference was a splendid one: we were all asked to contribute works we admired that might illuminate the overall theme—how narrative construction in the rendering of a case history challenges and informs the "construction" of objectivity. We assembled a shared bibliography of essays and books on narrative theory, hermeneutics, case narrative, narrative rationality, representation, the ethics of narrative, case performance, and objectivity: its uses and abuses. Best of all, we read the works of the seminar leaders: Kathryn's essays "Narrative, Literature, and the Clinical Exercise of Practical Reason" and "Remaking the Case," and excerpts from her *Doctors' Stories: The Narrative Structure of Medical Knowledge;* Tod Chambers' "From the Ethicist's Point of View: The Literary Nature of Ethical Inquiry" and "Dax Redacted: The Economies of Truth in Bioethics"; Suzanne Poirier *et al's* "Charting the Chart: An Exercise in Interpretation(s)" and her essay with Lyoness Ayers, "On Endings, Secrets, and Silences: Over-reading in Narrative Inquiry"; and William Donnelly's "Righting the Medical Record: Transforming Chronicle into Story" and "Taking Suffering Seriously: A New Role for the Medical Case History."

I recall that seminar as a nearly idyllic blend of intellectual intensity and emotional engagement. As we discussed the difficult issues our readings raised we enjoyed our very different perspectives. Why does medicine convey information in narrative form? At what point does the case become the person? Is that inevitable? Is that bad? How is the legal notion of "making a case" different from the medical act of presenting a case? Can you have knowledge without a context, or a discipline, or a language? What is involved in the refusal to narrate? We discussed the diagnosis of major illness as a speech act that creates a boundary, reinflecting every life act afterwards; we read Victor and Edie Turner's "Performing Ethnography" and Dwight Conquergood's "Health Theatre in a Hmong Refugee Camp"; and we tried out theater as a mode of narrative communication by dramatizing a case history. I remember both quiet moments and noisy ones: a walk and talk with the late Suzanne Fleischman, whose post-conference essay, "I am, I have, I suffer from…," offers a fierce challenge to labels that reduce the person to the disease, and a wonderfully noisy, crowded, sun-splashed architectural boat tour of Chicago that drew our seminar to a close.

In a Series of Cruxes. Ann Starr, *Where Babies Come From: A Miracle Explained* (1997). ann-starr.com

Just as we had all collaborated before the seminar on a joint bibliography and some initial questions, my notes from that week suggest we must also have been asked to contribute some "afterthoughts." Scrawled on loose-leaf tucked into the seminar binder I find my contributions:

> 1. Donna Haraway writes of situated objectivity—I want to suggest the key role of situated *subjectivity:* how subjectivity has a role within the frame of the objective to help us see a fuller picture.
>
> 2. We were (we now are, I really mean) an interpretive community. (As I remember this point, I was focused here on how the seminar exemplified the collaborative act of interpretation as an improvement on the isolated practice of autonomous analysis.)

That seminar challenged us to question the limits of objectivity and to plumb the relationship between personal narrative, medical experience, and embodied knowledge. It had a lasting impact on my work. Let me give two examples.

◆

When I participated in "Case Narrative and the Construction of Objectivity" I was writing *Liminal Lives.* The book I wrote next was a very different creature: *Poultry Science, Chicken Culture: A Partial Alphabet (PSCC).* Though in title it seems far from questions of medical humanities and bioethics, in fact as I explained in the preface, this book expanded on several of the themes and interests I had been concerned with during that seminar: "the social and scientific effects of the mining of female life—[albeit] now both human and avian, in the agricultural as well as the medical sciences—for intellectual lore and economic ore"(Squier 2011, 6). As I wrote PSCC I also drew on the wider set of scholarly approaches the seminar introduced through its challenge to objectivity and its broader understanding of narrative. I proposed situated subjectivity as another route to knowledge, reflecting my growing conviction that expert knowledge was but one kind of knowledge and not necessarily the richest kind. To write this book, I took "a vacation from the academic culture of expertise, where the only knowledge possible is the kind you already know," and embraced instead the position of the amateur (14). I adopted the productive form of ignorance that Shunruyu Suzuki describes as "beginner's mind." As he describes its effects, "In the beginner's mind there are many possibilities, in the expert's there are few" (1).

My second example of the seminar's influence may be my interest in graphic medicine—comics that address issues of medicine, illness, and disability—as part of the graduate seminars I have offered for several years now on graphic narratives and comics.[2] These constitute a bit of a departure from standard English doctoral seminars, since until very recently the literary canon has had little room for comics: graduate students must be risk-takers even to begin comics scholarship. Beyond the professional risk it may pose to decide to study comics, students are often anxious about issues of methodology. What critical and analytical tools can they use? One strategy already characteristic of much academic work on comics duplicates the critical and theoretical moves characteristic of mainstream scholarship: arguing for the aesthetic, philosophic, and thematic significance of the comic as a difficult but rewarding literary text. And yet… the lifeblood oozes out of the vibrant form that is graphic medicine if it is pressed into the standard literary critical mold. This more lively and authentic model of comics studies is hard for graduate students to access, however. Their graduate training emphasizes acquiring skills for the professional job market such as linguistic fluency, verbal and theoretical mastery, and critical acumen. Such training can actually work against them as they approach this new medium, inhibiting them just when they need to open up to different modes of perception and expression. They become so focused on critique and mastery that they are unable to become beginners.

They need an alternative perspective, and I have seized on one advocated in an essay published in 2003 by science studies scholar Bruno Latour: "Can we devise another powerful descriptive tool that deals this time with matters of concern and whose import then will no longer be to debunk but to protect and to care, as Donna Haraway would put it?….Is it really possible to solve the question, to write not matter-of-factually but, how should I say it, in a matter-of-concern way?" (232). Latour's essay was published during the backwash of the science wars, when the concept of social construction—the backbone of science studies for decades—was newly being deployed by the anti-science reactionary right to challenge scientifically accepted notions such as global climate change. His insight was that the habit of criticism which had given us such powerful analytic and deconstructive techniques had actually worked against the emancipatory hopes of science studies, by teaching the right how to deploy those same tools to challenge important scientific findings, and by alienating the public we had hoped to reach, and muting our message. Latour argued in 2004 that we should move beyond the academic habit of detached critique and instead "associate the word *criticism* with a whole set of new positive metaphors, gestures, attitudes, knee-jerk reactions, habits of thoughts" (247).

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Although Latour's reason for advocating an alternative to critique lay in his dismay at the declining public understanding of science, and mine lies in the wish to increase the public engagement of humanities scholarship, I share his sense that critique has become too easy and perhaps ineffective. The mask of the critic is too brittle to be expressive. What is hard, important, albeit at times embarrassing, is to speak to issues of concern: issues that move us, inspire us, and make us want to take action. To be true to the rawness, marginality, and urgency of the medium, I have come to feel, comics criticism needs to make connections beyond the university. It should admit urgency in tone and content. To do comics studies *on its own terms,* rather than as a pallid version of literary criticism, we need to find a way around all of these stumbling blocks.

The three responses I have developed to these challenges trace back, I believe, to Kathryn's seminar, especially to the ways it xposed us to the community building effect of starting from our own subjective experiences of medicine (as patients, physicians, nurses, caregivers) and encouraged us to try out different modes of narrative entry to the complex medical humanities questions before us, from theater and music to stunning visual art.

First, I have begun to incorporate into these doctoral seminars an hour of "studio time" (a chance to experience the *process* of making comics) and a focus on graphic medicine. While in the first and third hours of the seminar we proceed as usual, discussing the comic(s) assigned for that class meeting (its plot, graphic form, and narrative strategies) as well scholarly essays and the students' assigned response papers, in the middle hour of studio time we all—the students as well as the professor—*create comics.* We have a text to guide us; most recently we used Ivan Brunetti's *Cartooning: Philosophy and Practice* and Jessica Abel and Matt Madden's *Drawing Words and Writing Pictures.*[3] Frequently, we have a guest cartoonist who will introduce students to some of the basics of comics creation, both visual and verbal: drawing the face and the body, paneling, building tiers, composing a plot in word and image, and shaping the final product, a four-page comic of the students' own creation. But in the days where no guest cartoonist appears, we all simply draw together.

Second, in addition to building in studio time, I have also introduced a segment focusing on graphic medicine. Although these are graduate students in English, not medical students or medical humanities students, I do this because it makes my text-and-critique-focused English PhD students acquire a different way of engaging with comics, drawing on situated and embodied subjectivity to enhance their critical assessments. As we work our way through the basics of comics creation—paneling, speech balloons, emenata, gutters, tiers, and splash pages—their engagement with comics as a medium remains a loose one. They generally explore the different comics genres—superheroes, whimsical animals, evil monsters—in a mood more casual, playful, and detached than the one they customarily use in their written work.

Introducing this situated subjectivity, giving them the option of choosing a topic linked to medicine, illness, or disability for their four-page final comics and their scholarly final papers, I seem to make it possible for them to care in a more immediate and intensified way about the *form* and *content* of comics. They very quickly generate comics narrating a medical experience, whether their own or one of a parent, sibling, or friend. Their final seminar papers often take a similarly expansive perspective, drawing on their own subjective experiences, addressing issues of medicine, illness, and disability as relevant to, rather than outside the realm of, the contours of their work as literary scholars.

* * *

The seminar on "Case Narrative and the Construction of Objectivity" took place nearly twenty years ago. When I began it, I was a woman whose possibilities had been suddenly, painfully, and irrevocably changed by the surgery from which I was just recovering. As I participated in the seminar I encountered a range of perspectives on that surgical experience. I also acquired a more complex perspective on the post-surgery self I was coming to know. As I now reread one of them, Ann Starr's art book, *"Where Babies Come From: A Miracle Explained,"* it seems to me a lively example of graphic medicine almost avant la lettre. When the seminar ended, I left with a new and nourishing interpretive community and a renewed appreciation of the way attention to my own experience could loosen and deepen my own scholarly writing. I recall, during those weeks of recuperation before the seminar began, writing my surgeon about my plans to attend. I said I hoped it would help me think about "the ways that the gendered nature of narrative shapes what we hear/see/listen to in the range of narratives at play in the medical setting. (i.e., how does gender constrain & shape our sense of possibilities, realities?)" How objective that sounded; how subjectively I came to know it. So thank you, Kathryn.

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[1] This conference was sponsored by the Medical Humanities and Bioethics Program (then named then Medical Ethics and Humanities Program) of Northwestern University Feinberg School of Medicine, July 29-August 2, 1997. Tod Chambers was the co-leader of the conference, along with guest leaders William Donnelly and Suzanne Poirier.

[2] For more on graphic medicine, see http://www.graphicmedicine.org. With Ian Williams, I edit the new book series of the same name at Penn State University Press.

[3] I find Brunetti's inductive method of learning to draw appealing and his essayistic, professorial tone initially engaging, but by the end of the semester his approach to comics feels limited by its modernist, high art commitments. (My modernist literary theory students felt somewhat differently however.) Abel and Madden's textbook is welcoming, very nuts and bolts, and structured like a fifteen-week semester with reading and drawing assignments for each week. The drawback there is size: the very large format (8 ½ by 14) paperback is clunky to lug to class if you aren't an art student schlepping a portfolio. But Abel and Madden have a terrific website and blog where tips are available for anyone wanting to dip in to comics creation, and they are remarkably receptive to questions and comments from readers. I dream of the day they produce a standard-size version of their textbook for non-art student readers.

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SCOTOMA

Chih-Wei Wu, MD, MA

Scotoma, *n, pl* **-mas, -mata**
(Medicine/Pathology) A blind spot, a permanent or temporary area of depressed or absent vision caused by lesions of the visual system.

In 2004 Genentech sought and received FDA approval for a drug called Avastin (Bevacizumab) to treat metastatic colorectal cancer. Avastin is an inhibitor of vascular endothelial growth factor (VEGF), a key mediator for new blood vessel formation in tumor growth. The next year, Dr. Philip Rosenfeld recognized that macular degeneration in the eye and cancer metastasis have similar disease mechanisms, and he developed an innovative use for Avastin—injecting it into the eyes ("intravitreal injection") of people who suffer from age-related macular degeneration (AMD). Prior to 2005 there was no effective treatment for AMD, but Avastin worked because it inhibited the growth of abnormal blood vessels in the eye, a primary feature of AMD. The off-label use of Avastin revolutionized the treatment of AMD. Avastin has saved the vision of millions of patients worldwide by not only halting the progress of the disease but reversing its course. This medical breakthrough elevated Genentech to prominence in the field of anti-VEGF research and ensured Avastin a leading position in the market for AMD treatment.

The excitement over this new therapy quickly shifted to dismay when Genentech received FDA approval to treat AMD with a new drug called Lucentis (Ranibizumab) in 2006. Lucentis works in the same manner as Avastin, but it is packaged in individual doses and is FDA-approved for use in the eye. After Lucentis was approved, Genentech tried to restrict sales of Avastin for ophthalmological use. Genentech argued that the use of Avastin in eyes is off-label and there are concerns with repackaging this colorectal cancer treatment for injection into the eyes. Genetech's position aroused the indignation of ophthalmologists and caused heated debates in which the doctors claimed this was all about money. A single injection of Lucentis for AMD is $1,950. In contrast, a single off-label injection of Avastin in the eye costs only $17 to $50, because compounding pharmacies can split one vial of Avastin (the single-dose quantity for colorectal cancer treatment) into many doses for use in the eye. Given the fact that a monthly injection of either drug is suggested until the AMD lesions resolve (usually up to 2 years), using Lucentis significantly increases the financial burden for a patient. On the other hand, letting Genentech's earlier drug cannibalize sales of its later drug caused the company to bleed hundreds of millions of dollars. In order to curb its losses, in late 2007 Genentech attempted to bar sales of Avastin to compounding pharmacies so that ophthalmologists could not get Avastin for off-label use in treating AMD. Although Genentech's claim that intravitreal injection of Avastin for AMD is off-label is true, there were enough studies to convince ophthalmologists that Avastin was as effective and safe as Lucentis in treating AMD at that time.

As an ophthalmologist who was also pursuing a Master's degree in Bioethics at the peak of this debate, I have to admit that it was quite entertaining to follow all the battles between Genentech and Avastin supporters in the past few years, as well as informative to ferret out the ethics in their arguments and consider what was missing. From one side of the battlefield, Genentech consistently refused to acknowledge the benefits of Avastin in treating AMD, and bad-mouthed the off-label use of Avastin as unsafe and of doubtful effectiveness due to the lack of a large-scale randomized controlled trial (RCT) that the company itself refused to conduct. While bashing Avastin use for any eye indication, Genentech was aggressively expanding the market for Lucentis. It recommended using Lucentis for treating diabetic macular edema (ironically, off-label at that time) and implemented a secret kickback rebate program for physicians whose prescriptions of Lucentis reached a certain threshold.[1] Medicare reimbursement patterns suggest this strategy was effective: During 2008 and 2009 there were 936,382 injections of Avastin used to treat AMD, compared with 696,927 injections of Lucentis—a 57/43 split in favor of the less expensive off-label use of Avastin over Lucentis. The total cost for the Avastin injections was $40 million, but Medicare paid $1.1 billion for the lower number of Lucentis injections. To put this in perspective, had off-label Avastin use been the only treatment option available in 2008 and 2009, the US Medicare bill for AMD treatments would have been about $1.07 billion less than what it actually paid out during the same period.[2] On the other side or the battlefield, Genentech's concern with off-label drug use raised awareness within the field of ophthalmology. Ophthalmologists demanded that Genentech conduct either comparative studies between Avastin and Lucentis, or clinical trials on the use of Avastin for the treatment of AMD. This request was flatly rejected by Genentech, which is not surprising—it was not in Genentech's financial interest to establish Avastin's effectiveness in treating AMD.

There is a hidden prevalence of off-label drug use in ophthalmology, making ophthalmology one of the "therapeutic orphans."

As an ophthalmologist, I worry that the Genentech AMD drama is going to blur the focus on the larger (and largely unrecognized) issue of off-label drug use in ophthalmology generally. Ophthalmologists have been using drugs off-label to treat many eye diseases for a long time, and most of these off-label uses have become standard of care. For example, compounding pharmacies prepare topical antibiotics to treat bacterial or fungal corneal ulcers from the vials or ampules of the "parent" drugs that are meant to be injected intravenously for systemic infection; they also repackage injectable antibiotics to be used intravitreally for treating infectious endophthalmitis. Corticosteroids, such as Triamcinolone Acetonide or Dexamethasone, are also frequently injected into the eye to halt ocular inflammation. All treatments mentioned above are off-label uses

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because these drugs have never been approved to be administered by such routes. Oddly, ophthalmological prescription patterns are never in the spotlight when we talk about off-label uses, and I have never heard an ophthalmologist demand that pharmaceutical companies conduct RCTs to prove safety and effectiveness for the drugs we routinely use off-label.

There is a hidden prevalence of off-label drug use in ophthalmology, making ophthalmology one of the "therapeutic orphans." Rarely however are medical professionals (including ophthalmologists) or the public in general made aware of this. Pharmaceutical companies are responsible for imposing this predicament on ophthalmology by not providing sufficient ocular formulations, but what makes this situation worse is the profession's unconscious incognizance. For decades ophthalmologists have been prescribing drugs deemed standard of care regardless of the actual label information, and taking advantage of compounding when there is no FDA-approved, pre-packaged ocular preparations available. But it is this behavior—having drugs compounded on a regular basis to serve the therapeutic need—that has discouraged drug manufacturers from expanding drug indications to include eye diseases, and deterred pharmaceutical companies from developing drugs specific for ophthalmological use. If the profession does not acknowledge this plight, ophthalmology will continue to be therapeutically marginalized.

> The Avastin controversy reveals the scotoma of ophthalmology, the lack of awareness of its own prevalent use of off-label drugs in daily practice.

After Genentech refused to study the use of Avastin in AMD, the National Institute of Health sponsored a multi-centered RCT in response to the demands of ophthalmologists—the Comparison of AMD Treatment Trials (CATT). In April of 2012, after a two-year follow-up, the CATT concluded that Avastin and Lucentis are equivalent in treating AMD.[3] It seems to be a happy ending for patients and physicians because patients with scotoma resulting from AMD can now restore their lost vision with a less-expensive anti-VEGF drug. But I am skeptical whether it is a happy ending for medicine as a whole. The Avastin controversy reveals the scotoma of ophthalmology, the lack of awareness of its own prevalent use of off-label drugs in daily practice. It also reveals the scotoma of Genentech, which is the deliberate exclusion of Avastin as a potential good for the benefit of patients with AMD. Plainly stated, ophthalmologists don't know that they are frequently using off-label, and Genentech doesn't want to know that Avastin is as effective as Lucentis. In both cases, these are blind spots that have detrimental effects on the practice of medicine and patient care. The former might result from passive incognizance due to standard of care in ophthalmological practice, while the latter is willful ignorance inspired by shareholders and profits.

Now both Avastin and Lucentis can be effectively used to treat patients' blind spots, and that's a good thing. Treating the scotoma of the pharmaceutical companies and an entire medical specialty, however, will not be so easy.

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Sam Rockwell as Francis Flute and Kevin Kline as Nick Bottom in the 1999 Michael Hoffman film, *A Midsummer Night's Dream.*

On Not-Knowing: Flute's Solo

David B. Morris, PhD

> …the writer is one who, embarking upon a task, does not know what to do.
>
> —Donald Barthelme[1]

"My field is the history of thought," Michel Foucault said in an interview in 1982. "Man is a thinking being."[2] Foucault certainly taught an entire generation of scholars—a group particularly receptive to the overstatement—that knowledge is power. Non-knowledge and not-knowing, however, also claim an important if neglected place in human affairs, including medicine. Although knowledge is crucial in medicine, where lives are forever on the line, where something must be done, and where inaction is paradoxically an act, it is when we risk plunging into the depths of what we don't know (into our unplumbed and often dangerous confusions, anxieties, dreams, and sheer ignorance) that something like new knowledge and new powers can emerge. Not-knowing and non-knowledge must be circumscribed on behalf of patients, whose health and safety are at stake. Still, best-practice guidelines cover only a fraction of the medical encounter, and each patient brings unpredictable personal idiosyncrasies even to diseases with a well-known natural history. Medicine cannot stop work at the bright lines that mark off secure and perfect knowledge. Oddly, few experiences are more basic and less discussed in clinical medicine, science, and education than not-knowing.

"I don't feel that it is necessary to know exactly what I am," Foucault continues, as he segues into non-self-knowledge and builds toward his summary statement about man as a thinking being. "The main interest in life and work is to become someone else that you were not in the beginning. If you knew when you began a book what you would say at the end, do you think that you would have the courage to write it? What is true for writing and for a love relationship is true also for life. The game is worthwhile insofar as we don't know what will be the end."[3] *Game* is a potent metaphor for Foucault, for whom knowledge occurs only within varied discursive structures that he calls "*games* of truth." Whatever powers he envisions as wrapped up in knowledge and in thinking, then, also give ample latitude and something like free play to a dimension of the not-known.

The limits or disjunctions of power and knowledge—alongside a respect for the not-known—is a regular theme of Shakespearean drama. Characters distinguished for their knowledge (scholars, court advisors, or soothsayers, say) tend to lack power, while powerful figures such as kings and generals tend to lack knowledge, including self-knowledge. The results are often disastrous. Hamlet—Foucault's man as thinking being, philosophical to the core—famously veers between paralysis and spasm within the cut-throat world of power politics, while Marc Antony (a paragon of Roman power) loses his grip on both power and knowledge when confronted with the mysteries of Egypt and, of course, of Cleopatra. Comic moments, however, sometimes prove as significant as Shakespeare's lofty tragic figures in exploring the not-known and in exposing the limits of knowledge and power.

The limits of knowledge are doubly exposed (first by Shakespeare and again by director Michael Hoffman) in the celebrity-packed 1999 film version of *A Midsummer Night's Dream.* Shakespeare's long night's journey into erotic confusion shows how eros undermines both self-knowledge and self-control in lovers of every rank. The film takes an unexpected and unauthorized turn, however, in its depiction

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of the famous concluding play-with-a-play: the classical highbrow tragedy of Pyramus and Thisbe as performed—in honor of Duke Theseus's approaching marriage—by Bottom the weaver, Snug the joiner, Snout the tinker, Starveling the tailor, and Flute the bellows-mender.

The comedy of the conclusion—with the play-within-a-play an emblem of the failures of knowledge and power—depends on our recognition that the carpenter-director, Peter Quince, and his working-class amateur actors know almost nothing whatsoever about the theater. As they blunder on into the unknown, eager to please, they perform their ridiculously high-serious farce in front of an audience composed of smug know-it-all courtiers and aristocrats who want only a brief pastime before bed (and the rites of eros). The enthusiastic ignorance of theater displayed unintentionally by Peter Quince and his troupe—especially their unawareness of their own not-knowing, highlighted by cutting remarks from the duke and his court—plays out with traditional comic effect until, suddenly, the film takes its unauthorized turn.

Then it happens. Flute, dressed up in drag as the heroine Thisbe, bends over the apparently lifeless body of Pyramus, whose drawn-out bombastic death is overplayed to the hilt by the stage-struck egoist Bottom. All at once the high-flown diction stops. Flute removes his wig, lowers his voice, and speaks with an utterly out-of-character sincerity. In his ignorance of the theater, Flute apparently thinks that the lifeless body before him is not Pyramus but his old friend Bottom. The game has turned serious. Bottom is dead, or at least so Flute thinks. Yet Flute's confusion about theatrical make-believe somehow breaks through to clarities. His real emotion manages to reach beyond the surrounding falsity and (mis)representation in order to speak an honest heart's truth. It is as if, amid the pretense and silliness, amid the speciousness of court life, the overriding reality of death—cold as a winter wind—sweeps through the midsummer hall, and it is Flute alone (in his ignorance and not-knowing) who knows it: who truly *gets* it.

Flute's crucial moment of non-knowledge perfectly dovetails with a crucial and rich Shakespearean theme: the mysteries of theater. It's not just a gratuitous bit of comedy, then, that Flute fails to understand "Pyramus and Thisbe" as merely a play, a fiction, something not-real. In his comic misunderstanding that blends with a stone-cold moment of authenticity, Flute exposes what comedy traditionally opposes or at least diverts the audience from thinking about. Yes, love is linked to death, as tragedy makes all too clear. Yes, Bottom is *mortal,* a term that refers to humans as marked by their special relation to death. For all Flute knows in his unknowingness, his old friend Bottom really is dead, and the sudden loss hits him with the same real power and truth as if the bottom had indeed fallen out of his world. This is of course the great mystery of the theater: how falsehoods—representations on a stage—can move us to actual tears.

Not-knowing, in short, is fundamental to the theater, and (if all the world's a stage) it is basic too to the life that theater represents. Flute's speech in its single dramatic moment of authenticity weirdly manages to validate a truth concealed in all the trite metaphors, hyperboles, clichés, and sly double-entendres of romantic love with its overblown rhetoric of dying. (She "slayeth me," Demetrius dutifully parrots as the paint-by-numbers Petrarchan lover.) The fleetingness of the revelation, fortunately, helps maintain the arc—comic laughter redeeming tragic loss—in which the misplayed tragedy of Pyramus and Thisbe provides the turning point in Shakespeare's movement from discord to harmony. In addition, while the royal newly-weds and jaded courtiers look to the play-within-a-play for nothing but diversion, they are not all wrong. Isn't the promise of diversion—an evening's entertainment—what brings most audiences to the theater? The Shakespearean surprise involves a recognition that theatrical representations often give us more than we bargained on, confront us with something more than we thought we knew. Lies that tell the truth and hit home. Brain scans, MRIs, and mirror neurons, despite the welcome new information, are unlikely to hold all the answers about the human response to art or to dispel the basic cloud of un-knowing. When we enter the theater, we willingly enter into a realm given over, at least in large part, to the not-known.

Not-knowing is rightly a hard sell in medicine. "Doctors tend to have a fierce commitment to the rational…," as surgeon-writer Atul Gawande puts it. "If there is a credo in practical medicine, it is that the important thing is to be sensible."[4] Medicine sometimes seems entirely given over to the continuing quest for knowledge. Malpractice litigation awaits the physician who too whole-heartedly plunges into the deep end of not-knowing. In the service of patients, medicine rightly seeks to know as much as possible about wily human pathogens and the biological processes that underlie illness and health. Nonetheless, no matter how much medicine knows, mysteries of the not-known remain, defying sense, reason, and logic: sudden deaths, unexplained symptoms, benign chronic pain syndrome, flesh-eating bacteria, new diseases without a name and without a cure. Doctors, it seems, need at least a modest, unofficial, or passing acquaintance with how to proceed in the realm of the not-known.

Not-knowing, however difficult it is for health professionals to embrace openly, belongs to the territory that medicine shares with certain other human practices, from love to theater. In *A Midsummer Night's Dream* characters leave the rational and well-run state of Athens for the darkness of an enchanted wood that temporarily overturns what they know, or think they know, and yet the journey into not-knowing still manages to make contact with bedrock truths. Love *does* make fools of us mortals. (Our solace for mortality?) Less happily, partners who seem icons of faithfulness may, like the spotted Demetrius, betray us overnight. Quick bright things *do* come to confusion. In our everyday non-professional lives we tend to accept not-knowing and the not-known as inescapable. The way things are. As professionals, however, don't we tend to value or overvalue knowledge as an adjunct of personal power? Death, the silent companion of love and the daily opponent of medicine, is, as everyone knows, the archetypal not-known.

Flute's solo, in its fleeting, chilling contact with death, makes contact with the bedrock truth that love is possible only within a space closed off and thus defined or de-limited by what we do not know. Comedy, of course, refuses to linger over such implacable, unwelcome truths, which it admits only at an oblique angle, and thus it is important to recognize (even beyond its documented therapeutic effect) the value of comic laughter. Not-knowing often inspires anxiety—ask any student cramming for an exam—but it also contains a contrary and complementary link with pleasure. The puritan critics of Shakespeare's day, whose political allies eventually succeeded in shutting down the theaters, understood that comic laughter—in its links with pleasure, misrule, and the not-known—contains an implicit threat to order and to high seriousness. Mikhail Bakhtin, the great modern theorist of comic laughter, views carnival excess as calling into question and undermining every single-minded, solemn, monological system that proposes a stranglehold on truth. Among the systems that *A Midsummer Night's Dream* playfully undermines is of course the system of romantic love, still a staple of popular culture. Shakespearean comic laughter undermines not only romantic love, however, but also the contrary monological system on display in high-style tragic drama, where heroic love (as for Romeo and Juliet) appears violent, solemn, brief, bloody, and doomed. It is no small achievement that the comically misplayed drama of Pyramus and Thisbe transforms the disaster of high tragedy into an unexpected happy ending.

Good results, if not happy endings, may sometimes emerge from the dangerous plunge into not-knowing. Not-knowing, in such cases, is temporary and productive. It makes the various, endlessly deferred games of truth, in Foucault's term, "*worthwhile.*" Foucault does not trivialize the value of knowledge; no contemporary thinker has done more to probe the unexamined or forgotten histories of medical knowing. Foucault and Bakhtin also converge, however, in a recognition that medical knowledge—imperfect, provisional, and always changing—exists in productive dialogue with not-knowing. Why does a therapy that succeeds with most patients suddenly fail? Are clinical findings—replicated in multiple studies—nonetheless skewed (in a process called "publication bias") toward discovering exactly the effect they were looking for? Despite its patient-safety precautions and research protocols, medicine walks a tightrope where what is known with certainty serves like a balancing rod to steady our progress over a dizzying abyss of the not-known. No autopsy can answer all the questions, while comic laughter affirms a faith in good outcomes, unexpected recoveries, happy endings, what even a secular researcher has called *medical miracles.*[5] Not-knowing, if we let it, can bring us face to face with our limitations, which is itself a significant kind of limited knowledge.

Not-knowing may come in as many varieties as knowledge. It is certainly a positive step to eradicate error, demystify superstition, challenge stereotypes, and confront fraudulent substitutes for legitimate thought. Like it or not, however, medicine is a system of knowledge and, despite safeguards, is subject to the dangers implicit in other systems—from jurisprudence to theology—that reduce a heterogeneous world to the rule of order. How many futurists saw HIV/AIDS coming? Now Alzheimer's Disease threatens to overwhelm the American health-care system. The relentless medical quest after knowledge, facts, and information-technologies gives added resonance to Bottom's effort to recall his magical dalliance with the queen of the fairies. Kevin Kline delivers the famous speech, dropping Bottom's buffoonery, with the faraway look of a poet reaching for a knowledge just beyond the limit of his reason and senses:

> I have had a most rare vision. I have had a dream, past the wit of man to say what dream it was. Man is but an ass, if he go about t' expound this dream. Methought I was—there is no man can tell what. Methought I was, and methought I had—but man is but a patch'd fool, if he will offer to say what methought I had. The eye of man hath not heard, the ear of man hath not seen, man's hand is not able to taste, his tongue to conceive, nor his heart to report, what my dream was. I will get Peter Quince to write a ballet of this dream. It shall be called "Bottom's Dream," because it hath no bottom…[6]

Not-knowing launches us into a space without boundaries: it hath no bottom. It is a space in which our thinking, try as we might, cannot completely overcome its subjective bias. (William James—the only major American philosopher with a degree in medicine—put it this way: "human motives sharpen all our questions, human satisfactions lurk in all our answers, all our formulas have a *human twist.*"[7]) This subjective not-knowing, fundamentally different from know-nothing ignorance, honors a quality for which eros—like play—constitutes a complex metaphor: it gestures toward a bottomlessness, disorderly, chaotic, and even pleasurable realm without limits, a space always just beyond thought. It is less to be known, finally, than experienced, less to be validated as an object of cognition than (as John Keats wrote of poetry) proved on the pulses. *Lovers, make moan.* Medicine, like love, is not always practiced in the daylight of full knowledge but often, for better or worse, in the tragical/comical midsummer shadow of not-knowing.

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[1] Donald Barthelme, "Not-Knowing," *Not-Knowing: The Essays and Interviews,* ed. Kim Herzinger (New York: Random House, 1997), p. 11.

[2] Quoted in Rux Martin, "Truth, Power, Self: An Interview with Michel Foucault" (25 October 1982), *Technologies of the Self: A Seminar with Michel Foucault,* eds. Luther H. Martin, Huck Gutman, and Patrick H. Hutton (Amherst: University of Massachusetts Press, 1988), p. 9.

[3] Quoted in Martin, ibid, p. 8.

[4] Atul Gawande, *Complications: A Surgeon's Notes on an Imperfect Science* (New York: Metropolitan Books, 2002), pp. 109-110.

[5] Jacalyn Duffin, *Medical Miracles: Doctors, Saints, and Healing in the Modern World* (Oxford: Oxford University Press, 2009).

[6] *A Midsummer Night's Dream* (c. 1595-96), IV.i., in *The Riverside Shakespeare* (Boston: Houghton Mifflin, 1974). Brackets removed from several textual emendations.

[7] William James, "Pragmatism and Humanism," in *Pragmatism* (1907), *The Works of William James,* ed. Frederick H. Burkhardt et al. (Cambridge: Harvard University Press, 1975-1988), 117.

Been There, Done That:

Ethics Consultation and the Importance of “Not Knowing”

Martha Jurchak, RN, PhD

I recently found myself becoming impatient with how long it takes clinicians, family members, and patients to “get it.” I’d give them my formulation of their ethics problem and my guidance for how to extract themselves from it—something I know how to do after over twenty years of clinical practice, years of school, days of conferences, and countless hours reading—yet they were very slow to move toward resolution. Then one day I flipped through a women’s magazine while waiting to have my hair cut, and an article about sex reminded of the idea of the “beginner’s mind.” Yup: twenty years of work and my latest revelation is from *Glamour.* “Beginner’s mind” is a Buddhist concept of experiencing whatever is happening only in the “here and now,” the immediate moment, without expectation or anticipation of outcome. It reminds us that we do not know how a situation will unfold. This concept reminded me that while my accumulated wisdom from study and work is important for good ethics consultation, it is not enough. Knowledge and experience may help *me* understand problems and potential solutions, but in order to help those who bear the burden and responsibility of making critical decisions, I need to listen to their story, hear why they are struggling, and hold with them the feelings generated by a problem.

A position of “not knowing” and a willingness to discover, especially when the stakes are high and suffering abounds, are often both in short supply and crucially needed in ethics consultation.

My deepening understanding of how “not knowing” is critical to good ethics consultation was rewarded shortly after that fateful haircut. I got a succinct, almost blunt, text page from the Surgical ICU Fellow, but it’s a busy unit and I am familiar with the often crushing work load: “Family has been told patient critically ill—MSOF [multisystem organ failure] for days. They are religious. Want full treatment. Hoping for a miracle. Ethics consult needed.” I must admit that after receiving the page I was full of both familiarity and dread. “Okay, I’ve seen this before: a family doesn’t want to face a terminal disease, offloads their work of decision making to the hope that God will decide, and won’t engage with the team in the realities of the clinical situation.” But before I got to the waiting room I recalled the value of “hearing the story,” of immersing myself in the perspective of everyone involved, and in this case particularly the family.

The Surgical ICU Fellow wasn’t available when I called back so I went to the floor to get more information. The patient was lying motionless with her eyes closed, on a ventilator with an endotracheal tube in her mouth. She looked gaunt and frail. I found her younger brother in the waiting room reading a small prayer book. I introduced myself, explained what the ethics service does, and asked if we could talk for a bit. He was soft spoken, with a gracious, educated manner. I asked him to tell me about his sister. “She was the backbone of the family!” he said confidently and admiringly. He went on to tell me how she emigrated to Boston from Lagos, Nigeria and established herself working as a bookkeeper. She never married but devoted herself to her family and her work. He lived with her while he attended college here, and she was more like a mother and mentor to him than a sister. Now he was married to a physician and living in Baltimore, but he visited his sister frequently, and was also in close touch with their extended family in Nigeria. On this admission she had appointed him health care proxy agent, but they’d had no discussions about advance directives. What about her illness? Had she been sick long? “She was never sick! I can’t remember a day she was ill.” She was visiting him in Baltimore when she began to feel weak and had abdominal pain, so she cut her trip short to return to Boston to see her doctor. As soon as she got here she fainted, was admitted to the hospital, and they discovered her ovarian cancer—widely metastatic and beyond treatment. This was just four weeks ago. I was immediately

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Knowing (or Not):

Distinctions in “Bioethics” and “Clinical Ethics”

Virginia Bartlett, PhD

“You keep using that word. I do not think it means what you think it means.”
—Inigo Montoya, from William Goldman’s *The Princess Bride*

People make the slip all the time—in publications and presentations, in their pedagogy and their everyday practices: they use “bioethics” and “clinical ethics” as if they are interchangeable, as if the terms have roughly the same meaning. And there are other (rarer) moments when each term is used to refer to different practices and areas of concern. When used as distinct terms, those who engage in “bioethics” and those who engage in “clinical ethics” are recognized as coming from different backgrounds, with different emphases, such that knowledge or training in one does not necessarily equate to knowledge or training in the other. And the truth is this: despite the frequent conflation of “bioethics” and “clinical ethics,” there is a basic difference regarding *knowing* that highlights the difference between the two—which is why such distinctions matter.

Bioethics, as an academic field, is characterized by a basic concern for *knowing;* emphasis is placed on organizing, aggregating, and disseminating *knowledge,* with “scholarship, publications, and, to some degree, grant-writing [serving as] the quality indicators of success.”[1]

In contrast, the starting point for clinical ethics—as defined by clinical ethics consultation—is *not knowing;* emphasis is placed on discovery, on trying to understand the particulars of a multi-faceted, often uncertain and morally challenging clinical situation, and then, as Finder and Bliton note, to identify and clarify “what can be done about it, all without compromising the evident commitments held by those individuals in that situation.”[2] In other words, following from philosopher Richard Zaner, if the method of bioethics primarily concerns prescription, the method of clinical ethics primarily concerns an orientation—one in which we suspend or bracket typical understandings in order to attend to the particular context at hand, one in which deliberately shifting to not-knowing in order to learn is promoted. Identifying, clarifying, and addressing moral concerns in the face of dynamic clinical contexts, the hallmark of clinical ethics is thus part detective work, and part enablement and empowerment of the particular moral stakeholders.[3] As such, the disciplined orientation toward not-knowing creates the opportunity for both the therapeutic and the practice-oriented aspects of ethics consultation—such as discovering what matters in *this* set of circumstances for *these* participants—as well as for reflection on each circumstance as an example from which further understanding and additional meanings about the circumstances and the practice emerge.

This fundamental regard for *not knowing* in clinical ethics versus *knowing* in bioethics is no mere question of semantics or professional politics; it implies that the preparation and education of those who seek to practice as clinical ethics consultants entail fundamental differences from the preparation and education for those who would be “Bioethicists.” For instance, one announcement for a clinical ethics fellowship warns:

> This program is not intended to be an academic exposure to bioethics and the candidate is expected to have a solid academic knowledge of bioethics before they start the fellowship.[4]

Another announcement, quoted in Jeffrey Spike’s recent Commentary in *JCE,* describes the clinical ethics workshop being promoted as:

> the first opportunity for many aspiring ethicists to be on the front lines, to smell the smells, to carry a gun into the theater of war… a taste of a real clinical ethics training program... [5]

Both announcements imply that acquiring the academic bioethics “knowing” is not sufficient preparation for engaging in clinical ethics consultation—that the two are not so interchangeable as common usage would indicate.

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struck with how shocked and unprepared the patient and family must feel in the face of this sudden end-of-life event. I found myself thinking, "Imagine *my* brother, alone in another city, learning only a month earlier he had a terminal illness, and now facing his death." The team was waiting for the patient's brother to endorse a comfort measures plan of care. Knowing this, I asked him how decisions were made in his culture. He explained that decisions are made by the whole extended family, the tribe, and especially by the elders. He had been on the phone many times with his uncles and aunts in Nigeria and was planning on a call that night. From his perspective it was not up to him to make any decisions. I knew this was not what the team was expecting! And honestly, before I switched to my "beginner's mind," it wasn't what I was expecting either. I realized that the elders in Nigeria with whom he was communicating the team's message of "seriously ill" and from whom he was getting instructions to "pray and continue to treat her" needed to hear what the team was thinking but not saying—"she is dying." When this was communicated to them, it changed everything. She died with her brother praying beside her the next day with the family's agreement that her care in the ICU should focus on comfort.

Ethics consultation is not about coming up with the "right answer," telling people what to do, or any other form of the Solomon Approach of externally imposed "wisdom." Rather, the goal of ethics consultation is to help articulate different perspectives in order for people to hear one another—especially when they hold different points of view. Doing this well requires a perspective of "not knowing," from which I can ask questions and take a position of inquiry in order to find common goals and values. It requires a willingness to go into a situation not thinking that I can figure out the right answer before meeting the family, reading the chart, or talking to all of the significant stakeholders. The work is not about how clever I am. It's about how to walk with people at a time of distress and confusion, attempting to meet them where they are, while using inquiry to help them move toward an answer that is acceptable enough to everyone involved. Sometimes that's accomplished by explaining a policy, citing legal precedent, or describing the ethical principles that apply to the situation. Sometimes. But that is rarely what's most helpful. What's more often helpful is a willingness to enter the problem with a fresh and open stance, and from that position to help find the "best worst choice" or perhaps uncover a previously unseen possibility. A position of "not knowing" and a willingness to discover, especially when the stakes are high and suffering abounds, are often both in short supply and crucially needed in ethics consultation. This means saying, "I don't know what the right thing to do is, but I am willing to help you figure that out." But don't expect that this approach will be met with enthusiastic appreciation. In times of uncertainly people look for someone to tell them what to do, to illuminate "the right thing." Thinking of the Nigerian patient, I see in retrospect that if I hadn't consciously shifted my perspective from knowing to not-knowing, I would have been in danger of becoming ineffective in my ethics consultation work; potentially an insufferable "know it all." Perhaps "knowing" is both a strength and an occupational hazard of long experience in ethics consultation. Humility is natural in a new practitioner, but fades as time and experience accumulate toward expertise. Yet the American Society for Bioethics and Humanities identifies humility as a core character trait in ethics consultants for a reason. Decades into practice, I am relearning that wisdom in ethics consultation requires a healthy dose of humility, and that a beginner's mind is how knowledgeable people can remember how to not know.

Martha Jurchak is a 20+ year veteran of clinical ethics who has been involved in ethics consultation and ethics committee work in a variety of settings (home care, hospice, small community hospital, large teaching/research medical center), has written about ethics consultation, and has taught bioethics in college and post-graduate settings. She works at Brigham and Women's Hospital in Boston, and currently has the privilege of working with PI Ellen Robinson, RN, PhD and colleagues at Massachusetts General Hospital and Boston College on a HRSA grant supporting a clinical ethics residency for nurses. mjurchak@partners.org

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However, while such training courses may indicate a shift away from the long-standing assumption that education in and mastery of bioethics is sufficient for the practice of clinical ethics consultation, many of these clinical ethics training courses continue to reinforce the fundamentality of knowing. For example, as presented and promoted in both announcements mentioned above, the shift to clinical training is a shift from a required knowledge of bioethics to a required, carefully inculcated clinical knowledge (with characteristics still being determined, such "knowledge" seems a rough beast slouching forward, in Yeatsian fashion).[6] The emerging assumption appears to be that after appropriate intensive clinical training, one will *know how* to engage in the practice of clinical ethics consultation.

The new assumption, however, still misses the crucial point that preparation for—and practice of—clinical ethics consultation is fundamentally distinct from bioethics. The problem with the shift from "bioethics" knowing to "clinical ethics" knowing is that even the currently promoted "clinical knowledge" obscures the real, challenging, and poignant experience of not knowing that each clinical ethics consultant (alone, in groups, or on committees) faces at the beginning of each ethics consultation. Finder and Bliton frame the ethics consultant's responsibility this way: to do ethics consultation is to "become involved with a conversational exploration of matters," matters about which it "is not possible, of course, to know in advance—beyond common themes and typical questions—[so that] just which moral issues are actually presented by any specific clinical situation [must therefore] be learned at the time of the consultation."[7] Without bracketing one's diligently acquired bioethics knowledge or hard-earned clinical knowledge, without an orientation to begin, and continue in, one's own not-knowing—*which further demands the discipline to acknowledge the primacy of not knowing*—the clinical ethics consultant risks obscuring the not knowing (the moral questions, for instance) of those enmeshed in the particular clinical situation.

The distinction between *knowing* in bioethics and *not knowing* in clinical ethics raises questions that must be addressed—questions not just of politics or phrasing, but of practice and preparation, both as one moves from training into the professional role of ethics consultant, and also before one begins each consultation. When the standard frames for training in both bioethics and clinical ethics emphasize knowing, how ought mentors, colleagues, and institutions prepare and support "aspiring ethicists" in the disciplined practice of not knowing? How is one to deliberately, strategically, and humbly bracket the security of all one's actively acquired types of knowing? And finally, how can the clinical ethics consultant be available "to learn about moral life from the clinical circumstances of those who actually face these difficult situations,"[8] *except* by intentionally stepping out of the knowing of academic bioethics into the not knowing of clinical ethics?

Amid the passionate intensity found in most discussions of practice and preparation (and politics and phrasing), if we can begin engaging such questions in the spirit of not knowing, we might avoid the too-easy and too-risky slippage between "Bioethics" and "clinical ethics." Then perhaps our words might mean what we think they mean.

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[1] Jeffrey P. Spike, "Training in Clinical Ethics Consultation: the Washington Hospital Center Course," *The Journal of Clinical Ethics,* 23, no 2 (Summer 2012): 148.

[2] Stuart G. Finder & Mark J. Bliton, "Responsibility in Actual Practice: Consent and Participation in Clinical Ethics Consultation," in *Ethics By Committee: A Textbook on Consultation, Organization, and Education for Hospital Ethics Committees,* ed. D. Micah Hester (Lanham, MD: Rowman & Littlefield, 2008): 80, 89.

[3] See Richard M. Zaner, "Phenomenology and the Clinical Event," in *Phenomenology and the Cultural Disciplines,* ed. M. Daniel and Lester E. Embree, 39-66. (Dordrecht: Kluwer Academic Publishers, 1994).

[4] http://www.bioethics.net/jobs/clinical-ethics-fellowship-5/

[5] Spike: 149-150.

[6] ASBH Clinical Ethics Task Force, *Improving Competencies in Clinical Ethics Consultation: An Education Guide* (Glenview, Ill.: ASBH, 2009).

[7] Stuart G. Finder & Mark J. Bliton, "Responsibility After the Apparent End: 'Following-Up' in Clinical Ethics Consultation," *Bioethics,* 25, no 7 (September 2011): 416.

[8] Zaner: 60.

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NEXT THEME: “Bad Girls”

ATRIUM welcomes submissions for the next issue, “Bad Girls” (Winter 2014). Deadline for proposals is May 13, 2013. For more information visit bioethics.northwestern.edu/atrium or email Editor Katie Watson at k-watson@northwestern.edu.

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Snapshot

Misreading Montgomery

Tod Chambers, PhD

One of the textbooks that I often assign for a graduate class called “The Foundations of Bioethics” is an anthology edited by Nancy Jecker, Albert Jonsen, and Robert Pearlman. *Bioethics* includes introductions to various methods, often by figures in the field most often identified with these methods, such as Beauchamp and Childress on principlism and Jonsen on casuistry. But for the week we discuss narrative ethics I don’t assign the two readings that Jecker et al. offer as representatives of “narrative approaches” to ethics. One of the selections I have annulled from our readings in this anthology is from Kathryn Montgomery’s *Doctors’ Stories,* a canonical book in the medical humanities by my program’s most distinguished faculty member. I don’t assign it because *Doctors’ Stories* (like her other book, *How Doctors Think)* has little to do with medical ethics. Instead, both books are concerned with the epistemology of medicine and thus are perhaps best classified as representations of philosophy of medicine. Bioethicists have often misread Montgomery’s work, mistakenly understanding Montgomery’s topic of narrative in medicine to be the same as narrative in medical ethics, and thus have missed some of her key insights. This is best illustrated by comparing Montgomery’s work to that of Rita Charon, the author of the other “narrative ethics” reading in Jecker et al.’s anthology. Montgomery and Charon are both concerned with narrative’s role in medical practice, not its use in medical ethics. Where these scholars diverge hinges on the difference between is and ought—Charon argues that the way medicine is practiced is different from the way it ought to be practiced; Montgomery holds that the way medicine is practiced is the way it ought to be practiced. Charon contends narrative should be added in order to reform the practice; Montgomery contends narrative is already a part of medicine’s epistemology, and furthermore it functions in the way she thinks it should. Montgomery believes the reason we go to a physician is to have our illness stories transformed into medical cases—that is, into epistemological entities that can be used to ascertain what is wrong with our bodies. Medical humanities scholars in general believe that this transformation in some manner harms the patient’s story and thus the care of patients. Montgomery has been continually misread by medical humanities scholars as describing a detrimental process, yet for Montgomery this is a productive process. This misreading is indicative of the way medical humanities scholars have generally kept their focus on the prescriptive, rather than the descriptive. This misreading displays how many medical humanities scholars conceive of their discipline exclusively as an educational reform movement, which misses the opportunity to develop medical humanities into a true intellectual discipline.

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