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 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 1986 it was just she and Jim Bresnahan, the JD-PhD Joseph 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, 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 features our Marie E. Euromedicae (2001) is more than a mere assemblage to be squeezed, shaped and shifted to fill a space. I find quilling exquisitely satisfying for rendering the densely squashed and lovely in their capacity to capture the human body in cross section.”

Katie Watson, Editor
To see more of Lisa Nilsson’s work or to contact the artist, visit http://katiawatsonart.com

The Medical Humanities and Bioethics Program

Faculty

Catherine Belling, PhD—Assistant Professor of MHH&B
Rebecca Bradler, LCSW—Assistant Professor of Physical Medicine and Rehabilitation and of MHH&B
Tod Chambers, PhD—Associate Professor of MH&B and of Medicine; Director of MHH&B
Megan Czak-Strakos, PhD—Assistant Professor of MHH&B
MK Czerwinski, RN, MA—MH&B Artist in Residence
Alice Dreger, PhD—Professor of MHH&B
Joel Frazer, MD—Professor of Pediatrics and of MHH&B
Elisa Gordon, PhD, MPH—Research Associate Professor of Surgery (Institute of Healthcare Studies) and of MHH&B
Kristi L. Kirschner, MD—Professor of MH&B and Physical Medicine & Rehabilitation
Kathryn Montgomery, PhD—Julia and David Uihlein Professor of Medical Humanities and Bioethics; Professor of Medicine and of MHH&B
Debajyoti Mukherjee, PhD—Associate Professor of Physical Medicine and Rehabilitation and of MH&B, Director; Ethics Program; Rehabilitation Institute of Chicago Donnelley Family Disability Ethics Program; Assistant Director of Graduate Studies, MHH&B
Michael Oldani, PhD—Adjacent Professor of MHH&B
Suzanne Porier, PhD—Adjunct Professor of MHH&B
Sarah Rodriguez, PhD—Lecturer in MHH&B
Teresa Savage, PhD, RN—Adjunct Professor of MHH&B
Mark Sheldon, PhD—Senior Lecturer in Philosophy and in MHH&B
Kate Watson, JD—Assistant Professor of MHH&B; Editor, ATRIUM
Mark Waymack, PhD—Adjunct Associate Professor of MHH&B
Laurie Zohrt, PhD—Professor of Religion and of MHH&B

Staff

Myria Knox—Program Assistant
Bryan Morrison—Program Assistant
Thanks to Anna Fenton-Hathaway and Catherine Belling for proofreading assistance.

Northwestern University offers a MASTER OF ARTS in MEDICAL HUMANITIES AND BIOETICS; the interdisciplinary study of meaning and medicine. bioethics.northwestern.edu

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 marvelousoking 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, of communicating, of criticizing, of persuading, case, aphorism, rule, maxim…. Among other things, these revise the denomination 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 essays—cogitate with essay—so also, weighing, testing, being put to tests. Medical students are familiar with such tests, but largely as means to an end, knowledge, or “competence.” Essays, at their best, are about something else. 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 endomyembiosis. Thomas fretted over the words. There was no formula for the essay, but the essay 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 type writer: “What a marvelous inversion of anthropocentrism—and of competence”.

Montaigne’s essays were written in the first person and always enfolded personal experience—distinguishing the essay genre from the *compendium of adages*. They were written in French, reaching across class hierarchies. The essay was not systematic. 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, is annotated in Montaigne’s own hand. Revision and change were part of Montaigne’s concept of self. An 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’—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 irrogotic illness in our historical moment as well.

Montaigne is deeply skeptical about therapeutic intervention wider, 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.” 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 implies some of the most potent critique of the medical enterprise ever written.

(continued on next page)
Since Montaigne, throughout modernity, the essay has renounced strait and rigors of disciplinary genre—endeavors of systematizing, or presumptions to culminate in a “lower,” philosophical, judgment—in favor of a more particular than generalities. No 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.” Literary historian Georg Lukács called the essay “too… independent for dedicated service.” Adorno was more emphatic: “the law of the innermost form of the essay is to object, to propose improvements.” By [in] transgressing the limits, something becomes visible in the object which is its orthodoxy’s secret purpose to keep invisible.” The “form” of the essay for Adorno is an unexpected constellation among objects and concepts that escapes protocol, resists drawings, draws back veils on received wisdom.

This involves a somewhat opportunistic combination of secondary adjustments, conversion, colonization and loyalty to the innate group, so that… the innate will have a maximum chance of eventually getting out physically and psychologically undamaged.

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 discover on the merry-go-round when she finds that the one making 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 the society, it can simply be a heuristic device, a claim of the effects of social work, and whatever stage in life, is to look at one’s assigned role critically, skeptically. Even, for a moment, with disdain.

So role distance is a reflexive exercise, a form of self-examination and resistance. To think critically about one’s role does not require malice of relevance to the powers resisted—though that can be helpful in total institutions. It can simply be a heuristic device, a claim of the effects of social work, and whatever stage in life, is to look at one’s assigned role critically, skeptically. Even, for a moment, with disdain.

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 who clarify that critique is not, as is popularly assumed, and not a smear, but rather, it entails suspension of judgment. She cites Adorno in clarifying that critique is a mode of engagement with particular—so, always situated, never an abstract position. Critique is a practice. As yet practice, it 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. This brings Butler to a reprise of philosopher 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 anarcho, to render oneself radically ungovernable, but to ask a more situated and engaged question: “How not to be governed like that, in that way, by that power, in such and such an objective in mind and by that power, rather, it entails suspension of judgment.”

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 teachings 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. As such, Foucault’s “Enlightenment motto of philosophers 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 on Kant’s famous essay, “What is Enlightenment?” 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 functioning thinker, 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.

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" Faculty of medicine, law, and theology—were constrained in their exercise of reason by agendas of state, or by church. Only the cumulative certainty of the essay 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.

Medicine today remains an institution of tutelage, bound to instrumental utilities of the state, deeply informed by dogmas and by priory authority. How so can medical training comport with Kant’s sense of public freedom? This is difficult. Doing the orthodoxy of thought, like all professionalism, 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, and princely funding—encitements and fevers that can easily privatize, in the Kantian sense, the critical exercise of reason.

Foucault’s essay 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 brings us to Foucault’s essay, “Writings on critique,” which is a familiar fair practice in humanities, in qualitative social sciences, in humanistic inquiry. How does the medical and behavioral sciences, into training regimes seeking compliance with norms of behavior and competence? Can essays in medical development be a vehicle for, or extension of, experiences of role distance?

Foucault’s essay 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 Foucault’s essay, “Writings on critique,” which is a familiar fair practice in humanities, in qualitative social sciences, in humanistic inquiry. How does the medical and behavioral sciences, into training regimes seeking compliance with norms of behavior and competence? Can essays in medical development be a vehicle for, or extension of, experiences of role distance?

Foucault’s essay 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 brings us to Foucault’s essay, “Writings on critique,” which is a familiar fair practice in humanities, in qualitative social sciences, in humanistic inquiry. How does the medical and behavioral sciences, into training regimes seeking compliance with norms of behavior and competence? Can essays in medical development be a vehicle for, or extension of, experiences of role distance?

Foucault’s essay 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 brings us to Foucault’s essay, “Writings on critique,” which is a familiar fair practice in humanities, in qualitative social sciences, in humanistic inquiry. How does the medical and behavioral sciences, into training regimes seeking compliance with norms of behavior and competence? Can essays in medical development be a vehicle for, or extension of, experiences of role distance?

Foucault’s essay 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 brings us to Foucault’s essay, “Writings on critique,” which is a familiar fair practice in humanities, in qualitative social sciences, in humanistic inquiry. How does the medical and behavioral sciences, into training regimes seeking compliance with norms of behavior and competence? Can essays in medical development be a vehicle for, or extension of, experiences of role distance?
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 Montgomerie has noted the proximate relations some medical schools have with their parent universities, perhaps we can make better use of these relations. 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. 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 occa-
sionally—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 balmy 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 restraint. Emergence, not mastery, even for professionals in the making. Hereby.

Barry Sauders is a physician trained in internal medicine as well as an anthropologist of biomedicine with a doctorate in Religion & Culture. When he met Kathryn Montgomerie in 1985, he helped launch 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 (unrelated to discussions with Professor Paul Nussbaum) were adapted from a recent lecture to the 4th National Conference for Physician-Scholars in the Social Sciences & Humanities (Chicago, April 2013). "Eating Critique in a Total Institution." Barry.Sauders@med.uw.edu

5 Butler, ibid., 835.
6 Montgomerie, "That to Philosophy is to Learn to Die," The Complete Essays of Montgomerie, 56-67.
7 Good, "The Essay as Genre," 4-6.
8 In analytic terms used in Kathryn Montgomerie’s own work—e.g. “A Science of Individuals”—the essay’s thinking privileges the intrinsically narrative genre. Indeed, the essay may have its strongest affinities with the "philosophic puzzle" (law-bound) "problem of identity." A Science of Individuals: Medicine and Cassu arity, Journal of Medicine & Philosophy 14 (1989), 193-212. Kaufmann, R. Lance, The Skewed Path: Essaying as Un-Methodological Method, Diogenes 36 (1986): 68-92; 234. These terms originated with Wilhelm Windelband (1848) and Wilhem Dilthey.
11 It 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 b ookened 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 with the essay I would guess in 1986) with "What We Do." My current seminar students said that they only read the final week’s readings (including Kathryn’s) at the beginning, the seminar would have made much more sense.
12 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)
13 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 state-
14 ment suggesting that they would have no idea what they did unless we explained it to them would antagonize and insult these potential colleagues.
15 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 state-
16 ment is incorrect if we accept Donald Schon’s idea of the reflective practitioner, but Schon’s ideal practitioner reflects in a different way and on a different level than the reflection on medi-
17 cine offered by the humanities. The basic point is that we do not insult our medical (or scien-
18 tific) 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.
18 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.

Katz, Kathryn. The Future of Bioethics (2009). habrody@utmb.edu

Fox, Daniel M. Who we are: the political origins of the medical humanities. Theoretical Medicine 6:337-342, 1985.


On Explaining Medicine to Itself

Kathryn Montgomerie is one of today’s foremost philosophers of medicine. We are indeed fortunate that she has never 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 colleagues. 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 Schon’s idea of the reflective practitioner, but Schon’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.

Kathryn Montgomerie is one of today’s foremost philosophers of medicine. We are indeed fortunate that she has never 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 colleagues. 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 Schon’s idea of the reflective practitioner, but Schon’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.
Good doctoring: have we replaced reason with rationality?

The essence of good doctoring is summed up in the motto of the UK Royal College of General Practitioners: *sum* 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. 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 suitability 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 more thoughtfully identified 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 centered 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 of these moral, ethical and practical considerations not just about what to do in relation to the particular circumstances of that 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 against the wider needs of the population). "Good Medical Practice": Patients need good doctors. Good doctors make the care of their patients 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, experimental and difficult to codify (Polanyi, 1958).

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 the 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 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 putative government of the doctors—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 wielded by doctors as conferred by society (doctors symbolise trust, agency and authority). It follows that a powerful therapeutic alliance of reciprocal interpretation and projection (Balint, 1957). This “cognitive institution” facilitates doctor-patient interaction and produces a “cognitive 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.
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 & 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 valorizes 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 be 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 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, of the 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 points of view—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 virtus (integrity, honesty, and so on) and socially conferred power to build a healing relationship and take practical action in the patient’s best interests.

Acknowledgements: I thank Edith Schie, Rob Stones, Deborah Swingler and others too numerous to mention individually for conversations that inspired this article.

Tish Greenhalgh is a family practitioner and Professor of Primary Health Care at Barts and the London School of Medicine and Dentistry, London, UK. She has a longstanding interest in the philosophical basis of clinical practice and on narrative as a research and teaching resource, p.greenhalgh@barts.nhs.uk

References:


Good Medical Practice. London, GMC.


Pickard, S. & Rogers, A. 2012. “Knowing as Practice: Self-Care in the Case of Chronic Multimorbidity,” Social Theory and Health, 10, 101-120.


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 through the use of caffeine. It is this method 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). Yet 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 enhance performance. There is no scientific evidence to suggest stimulant use and intelligence is correlated or causally connected and sociological evidence to claim that they are not. Yet many participants in this discussion are choosing to know the future but not to know (or at least learn from) the past. 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 emphasize 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 enhancements (as opposed to, or in addition to being, stimulants). Reviews of scientific data strongly indicate that methylphenidate has little to no cognitive stimulant effects, and 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 of 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 attribute 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 habitual meanings will hold true for some time. Perhaps the most honest conclusion that we can reach about cognitive enhancement is that we actually 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 choosing to know 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 medication. 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 Nieuwerkerk Ethics, Delft University of Technology, University, Canada. This research encompassed ethical discussion, sociological profiles of use, scientific evidence for enhancement, and the role of discussants in creating or reducing the market for such drugs.

Selected References


C O N F E S S I O N A L
R U M I N A T I O N S  O N
A N  O C U L A R  C U R E  T E S T I M O N I A L

Brian Hurwitz, MD, FRCP, FRCPG

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 trial 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 mid-2000s, 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.12 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 risk (the RR lies within an interval that includes 1, signalling no net gain for the average patient from treatment (see Table). This finding 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 benefited from it; many, it was judged, would have improved spontaneously, either because the condition was self-limiting, 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. Some conjunctivitis was (and remains) very common—accounting for between 1/4-1/3 of all consultations in primary care—it was important to estimate the effectiveness of antibiotic treatment.

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.5-7 This second review confirmed the results of our first one: the RR 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 early in the 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 marginally better benefit in improving clinical outcomes”5—views which ran counter to my clinical impressions and beliefs. Very much more than 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 summarising 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 the same product was used instead of drops), in the measures and timings of outcomes assessed, and in placebo 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.

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 trial testimonial. It was I turning away from my own scientific work? 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 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 had 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 (continued on next page)
of patients who had been included in the first study, and this data pointed to a different conclusion.1 The 2012 study found higher odds of clinical benefit accruing at 2-5 days from an antibiotic, odds that were clearly maintained at 2-10 days and reflected the increased odds of pathogen eradication from conjunctival fluid at both time points (with no Cs 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 antibiotic treatment for conjunctivitis would not be necessary. The publications of these two studies 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.2

The credence given to antibiotic effectiveness in the most recent meta-analysis stems partly from substantially lower spontaneous resolution rates: 50% 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 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-standardized, uncontrolled, unplanned undertaking be taken into 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 needed not struggle to reconcile the actions I took with my tenure as the group of four who fared worse from no treatment. However, I have 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 against the desirability of no treatment. Another way of putting it if the group of four who fared worse from no treatment..."13

To mention intuition in a paper prompted by Kathryn Monteith’s work might seem risky in view of her critical elucidation in How Doctors Think of the misuse of this resource, which has been a theme in my practice for years. Doctors’ Stories, a change arising not only from intuition but from the one-at-a-time testimonies of patients talking about their symptoms and my convictions concerning of how they responded (or not) to treatment (or not).13

For the conclusion of this study varying from the findings and stance of EBM recommendations, and held its ground.

Brian Hurwitz has been a family doctor in Iowa. London for 50 years and Professor of Medicine and the Arts at King’s College London for the last decade, where he directs the Centre for the Humanities and Health, a Medical Humanities Research Centre funded by the Wellcome Trust comprised of clinicians, historians, literary and film scholars, philosophers, and psychologists working to elucidate the role of humanities’ methods (conceptual, visual, historical and literary) in understanding health care practices. brian.hurwitz@kcl.ac.uk; http://www.kcl.ac.uk/innovationgroups/eh/index.aspx

Acknowledgements

Many thanks to Aziz Sheikh, John Osborn, Andrew Herxheimer, Jeff Aronson, Elektra Kingma, David Hopkins, Neil Vernon, Jeremy Hen槐ke, Barbra Oxnam, John Launder, Mike Bepahorn, Irish Grennalgle and Katie Witness for helpful email discussions on earlier drafts of this manuscript.


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 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 and maybe 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. 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. Yet 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, he 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 the same problem: inadequate adherence to his medications. After we’d welcomed 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 any given event. 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. A couple of decades later Elizabeth Kübler-Ross fit denial into her 5-stage paradigm of how individuals approach their awareness of the my 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.

Yet Doug’s unwillingness to embrace the full implications of his cancer diagnosis not only 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 refused 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 on him.

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 realizing 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, shouted out, “I’m not dead yet!”

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 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.
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, seen him as a patient. I suspect Doug’s doctors consider him a perfect patient, I would not have gotten if I had seen him as a patient. I suspect Doug’s doctors consider him a perfect patient, seen him as a patient. I suspect Doug’s doctors consider him a perfect patient, seen him as a patient. I suspect Doug’s doctors consider him a perfect patient.

Rather than viewing denial in 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 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 he was a terminal disease. “There is no stage 5,” Hitchens famously informed us in a much-quoted TV interview. In his slender volume Mortality, 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, “…yet consciously and regularly acted as if this was not true, or as if an expectation 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.” In another study 26% of patients in hospice care had some degree of denial in the weeks and months before an imminent death. 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. Unreasonably 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.

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.

Lisa Sanders is an Assistant Professor of Medicine at the Yale School of Medicine and a Clinician Educator in its Internal Medicine Primary Care Residency Program. She is a columnist for The New York Times and author of Every Patient Tells a Story: Medical Mysteries and the Art of Diagnosis.

(continued from previous page)

6 Telford et al.
month at the time of my self-exam outweighed the benefit of potentially discovering a mass early, so I carefully orchestrated annual mamograms 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-mined 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 mistrusting 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 decided 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 really wrong.” Monitoring is visible on the films.” From this vantage point—therapeutically 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 hypochondriacal, 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, I knew that the alternative—and more culturally freighted—term “hypochondriasis” might come clean with my internist. Perhaps she would respect my disorientation, 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, and is, and usual she found nothing further during the physical exam. Six months of weaning before the onslaught of anxiety surrounded 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. “That was your call to me,” rather than hypochondriacal and that we needed a little rational reasoning to remind us what was what—and who was who. I felt shameed by her.
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 dissents 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 breast wall, a small dark sploch, interrupting the normal contour of the tissue. I move the probe away, turn it slightly, and move it back to the area. The sploch persists. I quietly speak to the technologist, "Mark this radial 9:06, 2 cm from the skin."

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 any more 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.
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 revolver 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 survival. Yet, when given the choice, 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. Rationalist economics aside, inserting the chance of death by bullet doesn’t just make us want to pay; it’s the only way to maintain certainty 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 life and at extremely low probabilities of death especially. 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 value of equivalent changes in probability. More recently, in an illustration that showed that certainty skews our judgments about the relative 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 judgments about the certainty of undertakings. The certainty which is needed to make sense of probabilistic data. If they were more precisely 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 exhausting 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.

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. Is this even possible to do so, we pretend to be certain.

Human belief may simply reflect my preference for certainty, or at least something that looks like it. Abraham Schwarz is an Assistant Professor in the Philosophy Department at IPFW (Indiana Purdue University Fort Wayne) and Associate Faculty member at the Department of Philosophy and the Institute of Psychological Sciences at the Mount Sinai School of Medicine. He continues to explore the interaction of epistemology and clinical decision-making as he branches out into questions of professionalism and bioethics. schwach@ipfw.edu

**References**


Diagnosis—
A Tool for Rational Action?
A Critical View from Family Medicine

Kirst Malterud, MD, PhD

“All diagnoses are provisional formulae designed for action.”

Henry Cohen, professor of radiology at the University of Liverpool, said this in his Skinner lecture in 1942. 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.” 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 Platonism, 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.” 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 aporetical 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 purely black and white, circumscribed by diagnoses abandoned the complexity of medical problems. Montgomery describes diagnosis as a plot summary of a socially constructed pathophysiological sequence of events. 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. 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.

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 life-world, a body of knowledge which is far from stable. 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.

The professional norm that objective signs are supposed to confirm subjective symptoms and thereby reveal monosynaptic 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. 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. Gradually, I realized that it takes some specific skills to navigate in these blurry medical waters without getting seasick. The basic yet significant competence is to transcend apparent incommensurabilities through advanced interpretative 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. Yet, an ongoing simultaneous attention to biomedical processes should never be neglected. A confined psychosocial perspective is not an adequate answer to the question of how people’s life-world 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. 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

(continued on next page)
Clinical practice, using knowledge about the patient’s problem definition, causal understandings, and expected course and outcomes, expectations about management, and self-assessed health resources as the foundation for rational hypotheses about what is wrong and what can be done.16 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.17-18 German historians Uexküll & Wesiack brought these points of view together in their comprehensive theory about human medicine.19 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.18 20 Conditions that are diagnosed as 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.20 21 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 common things occur most commonly. Symptoms are interpreted according to their probability. Montgomery discusses the probability challenges represented by the old medical adage “When you hear hooves, think zebras.”22 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 in, 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 poorly available evidence. We must act.”23 24

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 physician’s knowledge base, although it sometimes blurs the medical gaze with positive or negative stereotypes.24 25 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 requisite 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.26 27 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 multi-morbidity 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.28 Conditions that are diagnosed as regarded 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 diagnosis and the treatment path 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.29

6. 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 which based knowledge can be applied or not. Diagnosis is an interpretative negotiation of particular signs and symptoms and their development over time.25 In consultations without a clear-cut diagnosis, family physicians stage their conclusions on a different level than traditional disease diagnoses. Instead, they categorized problems as: 1) nothing dangerous, but it might look like… 2) testing by treating, and 3) tracking potential danger.30 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.31 For some, the diagnosis legitimized the symptoms as a disease; others felt better to suffer from fibromyalgia than from serious conditions. Yet, boredom, less, sadness and despair emerged when they discovered limitations in treatment options, respect, and understanding. The process of adapting to this diagnosis can be both 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 our experiences; for the physician, the diagnosis essentially serves, and for the family physician, the diagnosis to become a tool for rational action, w hich refers to the relevance and utility of information and interpretations and findings.32 33

A pragmatic approach is needed for diagnosis to become a tool for rational action. A fundamental mission of 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.34 The practitioner does not always know to name the diagnosis of a symptom to act (and watchful waiting is also a
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 therapeutic problem 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 is more than the name of the perpetrator causing the danger.1–3 Encountering the fluidity of clinical knowledge, the practitioner needs strategies beyond hypothetico-deductive logic, where the problem is solved when the hypothesis is confirmed or refuted. Semioticians Sebrok & Sebrok discuss the problem-solving demonstrated by the famous detective Sherlock Holmes as compared to clinical practice, applying perspectives from philosophical pragmatism.1–3 Peirce’s logic of abduction is a mode of inference different from deduction, inducing clinical clues of perception 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 I could. I can never bring you to realize how important the sleeves are, the suggestiveness of thumb nails, or the great issues that may be read from a boot-lace.”24 Tacit knowing is an essential aspect of such processes.2 The practitioner must learn to appreciate the capacity of notifying his or her way into the clinical 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 is sensuous, calling for more than rational logic to be understood and interpreted.3 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 the purpose of clinical application, and often remains validated regarding its transference towards broader populations. Yet the two types of knowledge construction are intimately interwoven in diagnostic interplay. Essential evidence from randomized trials and meta-analyses can inform, but never replace, individual clinical expertise in evidence-based health care.25 The practitioner must catch up with the best available evidence to make the necessary decisions, and is often confronted with a situation where a procedural verdict on the admittedly inadequate available evidence is necessary.26 Montgomery reminds us that medicine will never know everything for every case. The knowledge physicians have will not always translate into effective practice, and beyond the search for accurate predictors, uncertainty remains.26 What in hindsight may appear obvious may at the moment of action be much more obscure. Advanced gambles are needed, merging probabilistic competence and a psychological capacity to act under uncertainty.

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.27

In this role, interacting with the patient and translating the available signs to evidence, the practitioner is a co-creator of the clinical knowledge, not a neutral observer. Patient modern epistemology disputes the widely held medical belief of a “view from nowhere.”28 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.28 This does not mean that relativity rules with no general conclusions to be drawn; the role 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.29 Signs referring to a chosen perspective are given priority, while others are neglected. For example, visual cues are ranked higher than auditory cues by the medical culture.20 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 such patterns after awareness of the medical knowledge base—an andro-normative domain where male standards until recently have been universal.21,34 But even recognition of well established medical concepts, such as the typical rash of zoster, requires that the symptom pattern is known by the physician in advance.

Medical 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.31 Medical knowing is therefore the essence of the clinical method.32 Philosophers Arne Johan Verle- sen examines preconditions for moral performance in the individual subject.33 To identify a situation as carrying moral significance, a person needs the basic emotional faculty of empathy, while indifference and distance jeopardize morality. Verlesen 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 evidence that the professional is not adequately aware of, and only makes sense of evidence that he can literally and metaphorically grasp, clinical practice will be isolated from scientific knowledge and perspectives of the knower. Many people who are ill do not have diseases which can be classified according to our conventional taxonomy.38 Some may say the frontier view of the family physician is a marginal and distorted aspect of medical knowledge, which is any medical disorder, obesity, alcohol problems, and homosexuality, using a resource perspective that emphasizes that the absence of a strong side instead of focusing only on the problems. Her extensive publications include many empirical studies as well as meta-analyses and antioxidant mediators in medicine. Kirsi material has received the uclx://oxford references
3 Chinen AB. Modeling of understanding and metacognitive practice. Middle T: New 89; 9(3-45).

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.36

Epistemological marginality

Elaborating philosopher of science Thomas S. Kuhn’s theories, professor of family medicine Ian R. McWhinney delineates the assumptions 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.36 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.36

Kirsti Maletz is a professor of family medicine at the University of Bergen. Norway, also connected to the Research Unit for General Practice, Uni Research, and she also has a part time connection with the Research Unit for General Practice in Copenhagen. Her research explores different (continued on page 35)
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 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 reshaped (redesigned, revised) in the twenty-first century by the very forces of being 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.” 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 supposed to haul much, I suspect. Don’t be shy. I WANT YOU HERE!!"

She did indeed meet me at the airport, taking over my wheelee 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 Chimmins’ “From the Ethicist’s Point of View: The Literary Nature of Ethical Inquiry” and “Dox Redacted: The Economies of Truth in Bioethics”; Suzanne Poirier’s “The Literary Nature of Ethical Inquiry” and “Dar Redacted: contribution 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 remembered 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 Shunryu 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).

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.” Scrapped 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 remembered 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 Shunryu 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).

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.” Scrapped 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 remembered 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.
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 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, criticism needs to make connections beyond the university. It should admit urgency in tone and content. To do so means starting on its own terms, rather than taking 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 the critical work I believe, to Kathryin’s seminar, especially to the way it spoused to the community building effect of starting from our own subjective experiences of medicine (as patients, physicians, nurses, caregivers) and encouraged us to try 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 (in plot, graphic form, and narrative strategies) as well as scholarly essays and the students’ assigned response papers, in the middle hour of studio time we—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.1 Frequently, we have a guest cartoonist who will introduce students to some of the basics of comic creation, both visual and verbal: drawing the face and the body, paneling, building tiers, composing a plot in a word and image. During the final product, a four-page comic of the student’s 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 understandings. As we work our way through the basics of comics creation—paneling, speech balloons, emoticons, gutters, tiers, and splash pages—their engagement with comics as a medium remains a loosely held “glimpse” of the different modes of this genre—superheroes, whimsical animals, evil monsters—in a mood more casual, playful, and detached than the one they customarily use in their written work.

Concerning 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 pieces that embody, 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 related to, rather than outside of, the realms 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, “When I Was A Woman,” her graphic novel, a form of recuperation before the seminar began, writing my story 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/say/see in the range of narratives we 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.

Susan Spierer is Brill Professor of Women’s Studies and English at Penn State University and the co-editor of the Penn State Press book series, Graphic Medicine. She is the author, most recently, of Poultry Science, Gender and Culture: A Partial Alphabet, as well as Liminal Lives: Imagining the Human at the Frontiers of Biomedicine and Babies in Bottles: Twentieth-Century Visions of Reproductive Technology: autosp@m.psu.edu.

Words Cited
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 Poitier.

2. For more on graphic medicine, see http://www.graphicmedicine.org.
3. With Lab Waitz, I later wrote the new book series of the same name at Penn State University Press.
4. I find Brunetti’s inductive method of learning to draw appealing and his expository, philosophical tone engaging, but by the end of the semester his approach to comics faded limited by his modernist, high art commitments. (My modernist literary theory students felt somewhat differently however.) Abel and Madden’s book is wittily written, very rich and hard, and structured like a fifteen-week semester with reading and drawing assignments for each week. The drawback there is size: the very large format (8.5 x 11) paperback is clunky to lay to class if you aren’t an artist subbing a portfolio. But Abel and Madden have a terrific website and blog where tips are available for anyone wanting to dip into comics creation, and they are remarkably receptive to questions and comments from readers. I dream of the day I introduce a standard-size version of their textbook for non-art student readers.
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. Genentech’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. 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 was actually paid out during the same period. 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.

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...
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 insensitivity. 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—havíng 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.

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.1 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.

only within a space closed off and thus defined or delimited by the theatrical setting. Comedy, of course, relies on a Pyramus and Thisbe provides the

 detailing the theatrical setting. Comedy, of course, relies on a...
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 me 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.

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

(continued on page 44)
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 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 is, but I am willing to help you figure it out.” But don’t expect that this will be met with enthusiasm appreciation. In times of uncertainty 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 characteristic in ethics consultants for a reason. Do I have ethics consultation skills? Yes. But in any practice, I am learning that wisdom in ethics consultation somehow in this 被动语态结构是一个绝妙的句子，它展示了作者的高超英语水平。作者通过这种结构表达了对“不知”的态度，这在不同的文化背景中是常见的。然而，这项研究却要求我们了解它在实践中的应用。
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. Montgomery 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. 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.

Tod Chambers, PhD

Misreading Montgomery

Tod Chambers is the director of the Medical Humanities and Bioethics Program at Northwestern University’s Feinberg School of Medicine. His areas of research include the rhetoric of bioethics and cross-cultural issues in clinical medicine. t-chambers@northwestern.edu