Narrative evidence based medicine

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We work in the dark—we do what we can—we give what we have. Our doubt is our passion and our passion is our task. The rest is the madness of art.

Henry James, The Middle Years

Henry James’s story The Middle Years represents a writer, Dencombe, in the prime of his writing life but the decline of his physical life. Seriously ill as the reader meets him, he meets up with Dr Hugh, a brilliant physician and a skilled reader who has fallen head over heels for Dencombe’s novels. Dr Hugh is, narratologically, Dencombe’s “ideal reader”, schooled in, and sympathetic to, the writer’s project. In the epigraph above, Dencombe articulates his credo as he embraces, in the waning hours of life, his stilling love affair with the mystery of life’s questions. The “rest” that constitutes the madness of art is that which lies beyond doubt, namely, certainty. By placing the certain in the realm of art—and of madness—James tells us a great deal about his own aesthetic experience, his path toward knowledge, his sources of light, and the realms of his doubt.

For doctors, what lies beyond doubt, passion, and task feels less like the madness of art and more like the maddening quest for answers. Taunted by death, chilled by the unknown, reproached by ambiguity, we doctors defy the dark, brandishing whatever truthiness we might have at our disposal. Humours, meridians, alchemy, or molecular biology, our scientific beliefs themselves are not as important as is the slim and ultimately betraying comfort they temporarily provide. With rare exceptions (William Osler’s bedtime reading, Anton Chekhov’s short stories, or William Carlos Williams’s poems), doctors seek to solve their doubt not with James’s creativity and beauty but with data.

Medical practice is poised astride insoluble tensions between the known and the unknown (or at least the knowable and the unknowable), the universal and the particular, and the body and the self. Nested, these tensions beget and amplify one another. The unwary physician, caught in the headlights of one of them, usually succumbs to the paralysing effects of all three, often without knowing what waylaid him or her on the country road to begin with. The tensions have yet to be adequately captured in language. We try to depict the oppositions so that we can at least see what challenges us, but such simplifying formulations as art versus science or nice doctor versus good doctor or illness versus disease do not convey the fundamentality of the conflicting forces. The question is not simply whether medicine is instrumental or imaginative, or whether it requires compassion along with competence, or whether humanities should be required in the medical school curriculum. It has, rather, to do with the nature of health, the problem of pain, the sources of suffering, and the fact of death. These questions are as big as questions get, bristling with profound ontological and existential considerations of human worth, of singularity, of chance, and of form.
The tendency to reduce such tensions to their caricatured bare bones prevents us from ever seeing them full in the face. Whether the issue arises from the laboratory, the clinic, or the polis, we do not serve ourselves or our patients well by underestimating their complexity. To face them fully, one needs at one’s disposal a way of knowing that exceeds the technical or the theoretical, that is equipped to absorb and comprehend the situated, unruly, contradictory, meaning-saturated levels of experience. One needs charts and soundings to navigate fraught channels, but only the seasoned river pilot has the lived-in wisdom to find the way through safely. Aristotle calls this kind of wisdom *phronesis* while philosophers and clinicians call it narrative knowledge or reflective practice—it is a way of knowing that recognises the known/knowable, the unknown/unknowable, the universal, the particular, the body, and the self. Whether of the river bed or the human life, this earthy and inhabited knowledge resists the urge to polarise, to flatten, to depersonalise, or to cool. Instead, it recognises, it attends, it reaches, and, with courage and imagination, makes contact with others. It hails doubts not as affronts to one’s power but as mysteries to behold. Such a form of knowing might help medicine to countenance its underlying tensions, and it is exactly to harness it for clinicians that the field of narrative medicine has recently emerged.

These tensions today are being enacted on the stage of evidence. The growth of evidence-based medicine (EBM) offers hope that good data can point to good actions. Building on the work of Alvan Feinstein, Gordon Guyatt, David Sackett, Brian Haynes, and others, EBM proposes that clinical decisions be made on the basis of trustworthy evidence, deployed by clinicians who use their clinical judgment and take into account the patient’s values and circumstances. Because the movement to date has focused on criteria for the trustworthiness of evidence (randomised controlled trials are the best and anecdote is the worst), EBM has earned the reputation of dismissing the importance of the singular predicament of the patient and the individual judgment of the doctor. EBM has inflamed clinicians who feel belittled by it, calling it elitist, authoritarian, imperialising, and even fascist. EBM proponents answer that clinicians’ considerations of patients’ circumstances and values are not ignored by the model and that the hierarchy of evidence is a scientific tool aimed at assisting physicians and not dictating to them. Nonetheless, even proponents agree that they have a poorer handle on how to factor in clinical judgment and patients’ circumstances than they do how to judge the hierarchies of evidence.

At the same time that interest soars in the evidence-based “right” decisions—an interest that privileges the known/knowable, the universal, and the body—we see a growth in medicine’s interest in the unknown/unknowable, the particular, and the self—in patients’ lived experience, illness narratives, and the interior lives of clinicians. For years now, the fields of narrative medicine and literature and medicine have reminded doctors that illness unfolds in stories, that clinical practice transpires in the intimacy between teller and listener, and that physicians are as much witnesses to patients’ suffering as they are
fixers of their broken parts. More and more clinicians and trainees are being encouraged to write about their clinical practices so as to develop the capacity for reflection. New clinical routines that provide patients with copies of what their doctors write about them or that encourage patients to contribute directly to their medical records are challenging traditional notions of authorship of the clinical record and, indeed, of the illness. Forms of medical interviewing that resemble ethnographic field work or psychoanalytic listening rather than bureaucratic check-listing are on the rise. Whether they call their enterprise patient-centred care, mindful practice, relationship-centred care, or narrative medicine, many clinicians and patients are converging in a federation that proposes recognition of singularity, respect for illness's mystery, and attention to the embodied self as the fundamentals of health care.

Some authors have addressed the need to resolve the potential conflict between the objectivity of EBM and the narrative singularity of both patients' and clinicians' lived experience. They have considered “narrative-based medicine” as a possible remedial avenue. Building on their work, but trying to avoid the implied opposition (must one choose between “narrative-based” and “evidence-based”?), a group of clinicians and scholars at Columbia University has undertaken a programme that explicitly integrates these realms and tries to illuminate fundamental unities between them. Calling the effort “narrative evidence based medicine” (NEBM), our project recognises the narrative features of all data and the evidentiary status of all clinical text. The skilled clinician does not first collect and deploy evidence and then soften it up with narrative; rather he or she is always already embarked on grounded, rigorous, personal, particular, and perilous interpretations that, like any hypotheses, can be tested for trustworthiness and utility.

This effort has drawn us to a variety of texts—contemporary novels, grounded theory, papers from the EBM literature, patient-written illness narratives, aesthetic theories of illness, and phenomenological theories of embodiment. Together, we struggled to interpret transcripts of ethnographic interviews, uncovering the complex interplays among text, reader, and teller that operate no matter when one person tells another person that something happened (literary scholar Barbara Herrnstein Smith's definition of narrative). In the near future, we plan to study clinical interactions to try out our interpretive strength in vivo. We are seeking funding to study NEBM methods in translational research at the so-called “T3 block”, the final step in the pathway that leads from research idea to improved patients' outcomes, namely, patients' own decisions to accept and execute offered interventions.

We are coming to see that the three fundamental tensions upon which medicine finds itself—known/unknown, universal/particular, body/self—are reflected in the three circles of EBM. Clinical evidence examines the known and unknown. Clinical circumstances integrate the universal and particular. Patients' values speak to both body and self. By virtue of its capacity to recognise the tensions fully, narrative medicine can lend to evidence-based medicine the methods of respecting its three circles of attention. It is not through dearth of desire but dearth of methods that EBM has yet to achieve attention to all three circles. With narrative medicine's methods, EBM can indeed be true to all its promises.
If Dr Hugh is Dencombe's ideal reader, he also happens to be Dencombe's ideal doctor. Try as, in fact, he does to marshal the forces of his local truth, he cannot cure Dencombe but can only sit by the dying man's bedside, keeping vigil, offering witness to his patient's greatness, confirming his worth. We in NEBM recognise, with Dr Hugh's model of the congruence between the ideal reader and the ideal doctor, that our duty lies not only in unearthing answers but in using our earthly lived-in ability to tolerate the unknown and the unknowable, to attend to the singular, and to include in our care both the bodies and selves of patients and doctors. Come to think of it, Dencombe's credo is not a bad fit for medicine.

The NEBM Working group at Columbia University: Herbert Chase MD (medicine and informatics); Michael Devlin MD (psychiatry); Craig Irvine PhD (philosophy and narrative medicine); Rishi Goyal MD (English and emergency medicine); Mindy Fullilove MD (psychiatry and public health); Helen-Maria Lekas PhD (qualitative medical sociology); Jeremy Simon MD (philosophy and emergency medicine); Richard Younge MD (family medicine).

Further reading


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