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To See the Suffering

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Abstract

The author notes the impressive growth in medical humanities programs, scholarly journals, textbooks, and national and international conferences as well as the convening of two recent national forums or boards addressing the potential of the humanities and the arts to improve medical practice. She also notes that the field of medical humanities seems to have shifted from addressing topics on the margins of medical education to equipping students with the foundational skills required for effective doctoring. This Invited Commentary proposes a number of personal, relational, and interpretive consequences to rigorous training in the humanities or the arts that might lead to improvement in the skills of doctoring. Where else but in hospitals with very ill patients and very young doctors who care for them are such skills needed the most? The author suggests that to see the suffering might be what the humanities in medicine are *for*, and that those who become capable of seeing the suffering around them in medical practice both experience the cost of countenancing the full burden of illness and death and, simultaneously, comprehend with clarity the worth of this thing, this life.

I received an e-mail from a recent graduate from my medical school, a liberal arts major in college who had had rigorous training as a fiction writer. She sent me a reflection she had written about a patient who died, including these lines:

> He said: “Whenever the doctors ask if I want CPR, the shocks and tubes and all that, they always say, *if something were to happen, God forbid, God forbid*. But look around. God’s not forbidding anything.” I sort of knew what he meant.[1]

Having worked closely with this student during her clinical and creative training, I have observed that she sees things that not all medical students see and hears things that not all medical students hear. These seen and heard things are part of her reality. For this student, training as a writer is not a civilizing veneer, not a *lagniappe* to her medical practice. No. Either her writing skills and grounding in philosophy and literary studies give her capacities to see things that other medical trainees might not see or the fact that she *has* those capacities attracted her to becoming a writer and majoring in liberal arts. In either case, she exhibits, in her medical work, the capacity to see the real, the hyperreal, and the hyporeal

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simultaneously, that is, to be aware that aspects of a situation might exist above or below the plane of the observable reality. She exhibits the capacity to see in curved lines, to wonder all the time about the unseen, the seen-by-others. Such sight transforms her practice.

Those interested in the humanities in medicine are anxious to pose the urgent and perhaps coming-to-be-answerable question: Does rigorous humanities training before and/or during medical school produce physicians with consequential clinical capacities not seen in the nonhumanities-trained students? During the early decades of bringing humanities training into medical education, it was enough to hope for a gleam of creativity in the midst of rote learning or an effective way to teach students to respect their cadavers in the anatomy lab. Over time, we have accrued evidence of the consequences of humanities training for physicians. Studies have compared humanities majors to nonhumanities majors in U.S. medical schools that assure us that the humanities majors fare as well academically as their science or social science counterparts.[2,3] Studies have also described the benefits of individual medical school courses in humanities and the arts in encouraging desirable cognitive, advocacy, affective, and creative consequences for students.[4,5] The impressive growth in medical humanities programs, scholarly journals, textbooks, and national and international conferences demonstrates both the demand and the capacity to widen pre-medical and medical education to include humanities and the arts.[6,7]

By now, as we have become more rigorous in our own scholarship in the disciplines of philosophy, literary studies, critical theory, qualitative social sciences, creative writing, and visual arts, the immensity of our work comes into view. The fact that we have had such a hard time agreeing on what even to *call* this thing we do—medical humanities, health humanities, narrative medicine, biohumanities—testifies to its magnitude.

I suggest that medical humanities' stakes have matured from addressing topics situated around the margins of medical education to equipping students with the foundational skills required for effective doctoring.

In 2016, the president and chief executive officer of the Association of American Medical Colleges and the chairman of the National Endowment for the Humanities met for the first time to consider joint programs to support teaching humanities in medical school, which resulted in a national 2017 thought leader forum on humanities and the arts in medical education with plans for on-going collaboration. Also in 2016, with the partnership of the Smithsonian Institute and funding from the Andrew W. Mellon Foundation, the National Academies of Sciences, Engineering, and Medicine's Board on Higher Education and Workforce initiated an examination of the outcomes of efforts to integrate education in the humanities with education in science, technology, engineering, and math, including in both pre-medical education and medical school curricula.[8] In view of such high-level interest in the outcomes of work in the medical humanities, we now have the duty to conceptualize and articulate robust assertions about the contributions the humanities make to medicine. Beyond our early formulations that humanities help students tolerate ambiguity and respect the perspectives of patients and families, can we name, in muscular terms, those humanities-related foundational skills required for effective doctoring?

Let us consider a medical student with rigorous training in the humanities or the arts. What might humanities training have added to his or her clinically salient skills? Is it the case that, by virtue of training in philosophy and literary theory, our student has developed the hard-won skill not just to appreciate the observation that each person constructs his or her own perceived reality but also to live in the glare of this observation's truth? This student has perhaps achieved access to deep scathing knowledge about truth and reality—their fragility, their fungibility, their trustworthiness, the fact that you can or maybe have to stake your life on them. These skills might equip the student with tools—courageous thinking that does not veer around paradox, methodical consideration of an idea's or situation's contradictory dimensions, practice in holding many unrelated things in one's mind at the same time, and habits of living inconclusively *toward* new ways of seeing—with which to confront, and then perhaps to treat, random unfair illness in the relative strangers now in his or her care.

Our student can have learned from training in phenomenology how to make intersubjective contact with another person by together gazing at the same thing, be it a poem by Wallace Stevens, a bars-of-color painting by Mark Rothko, or a mass in the head of the pancreas on an MRI. His or her phenomenological and creative trainings could provide the means to live with a body not as a vehicle, or a burden, or a trophy but as the only medium through which a person can join in the universe of the real. Having a body means living in time, and our student's capacity to live with a body brings with it the realization that he or she, too, will die. ("Let be be finale of seem/The only emperor is the emperor of ice-cream."[9]) Enduring a life in time unlocks access to memory and anticipation, which are the obligatory avenues to becoming autobiographically a person. The affective and creative parts of the student's training can engender powerful emotions of rage, love, helplessness, power, and ecstasy. Not that such emotions are undergone only through books or spectatorship, but the capacity for such emotions, the volume of the emotional amphora of the self, is always widened, deepened, made more capacious, never-endingly, through our brushes with the beautiful, the horrible, and the imagined. And the emotions themselves, once befriended, unfurl in real relationships with real people, quite apart from one's aesthetic or intellectual life.

Where else but in a hospital—full of very sick people and very young people trying to take care of them—is such knowledge most necessary? Where are the stakes higher for such knowledge than in conversations with suffering persons about illness and death? Giving conversations about serious illness the practical name of "goals of care" conversations and offering communication skills training in conducting them does not diminish their unspeakable gravity and does not bring the conversationalists away from the edge of the abyss. To talk with a seriously ill person about his or her near future brings both conversationalists straight toward what it means to be alive, what it costs to be alive, what is this life of ours, this life of ours?

Not only those of us engaged in humanities and medicine but most clinicians, scholars, and scientists in health care have come to understand, by now, the morbid complexity of illness and health. No one disagrees that each patient hosts his or her diseases in his or her own way. Whether the front door to this realization is a genomically driven precision medicine or socioculturally informed personalized medicine (they will, I suggest, come to be seen as the same thing), we are converging on an awareness of singularity and patient uniqueness. With

the help of lessons from the humanities in nomothetic and narrative knowledge, we are able to acknowledge details about patients' lives that may seem tangential to their medical problems and treatment but are core to what they value about themselves. Even the most biomedically focused among us grope for the means to comprehend the behaviors and decisions of patients, especially when they conflict with medical recommendations or with our own choices. Without humanities-derived introspection to identify our own governing values, we may have difficulty recognizing values in others that conflict with those we hold. The basic skills of imagining and respecting worlds different from our own can be developed through disciplined reading, theatre-going, cultural exposure, and attentiveness to human behavior; these skills prepare us to accept as valid realities that do not replicate our own.

The specific situations of health care, both the acute or end-stage diseases seen in the hospital and the longitudinally unspooling illnesses that braid through our outpatients' lives, deal out to us existential challenges of the unsolvable sort. There is no logic to be made of wordless pain or abandonment at the end of life; there is no sense to be found in end-stage disease in a neonate. Such core concepts as innocence and agency are emptied of meaning, while the painful states of blame and shame and guilt perfuse the wards and waiting rooms of our worlds. As sense-making, meaning-seeking creatures, we observers and participants in such challenges need means to come to terms with the surreal paradoxes of unearned suffering. It is not through rehearsing the mechanisms of actions of diseases or their treatments but through being present to individuals' lived experiences of illness that we might find at least enough meaning and sense to live by.

Here is a painful and bifurcated truth: Facing head-on the realities of serious illness in our settings of contemporary Western health care takes the savage imagination to recognize and then countenance the facts of suffering: unfair, unwarranted, vengeful, impersonal, neutral, demolishing of those whom it visits, without consolation, without the silver linings so often fabricated by those it fingers. There are only two paths open to those who must witness suffering: (1) pretend it is something else—predictable, resectable, eventually curable, spiritually enhancing, the thing that happens to others—or (2) see it fully and endure the sequelae of having seen.

Training in the humanities lets one see the suffering. This is, I suggest, what the humanities are *for.* Unlike Lot's wife, who was turned into a pillar of salt by looking, despite a command not to, at a scene of suffering (Genesis 19:26), there is something to be had for the seeing, as long as one has prepared oneself for the potentially blinding or paralyzing vision. What one gains by the sight of suffering is the knowledge of the cost of this life. If given proper training in the humanities, this knowledge is available to the interns who do not retreat into the instrumental, to the clinicians who can bear to look full in the face at that which stalks their patients. For those who are prepared, the sight of the laden, heavy, dragging reality of illness and dying comes with its antinomous double: a view of that floating bridge[10] between here and there, that fragile passage between the knowable and the unknowable, that ground each one of us stands on in each lived moment (now, here, as you read my words; now, here, as I write them) with no guard-rails, no sign-posts, no map, no territory; a clear-eyed discernment of this thing, this life, its worth.

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