Editor's Column

Endangered

ONE MOMENT THE STREET WAS QUIET AND DRIZZLY, SO FAMILIAR that I barely gave it a thought. The next moment the headlights were upon me, direct, blinding, a flood of illumination so incandescent and unexpected that what gripped me wasn't fear but stupefaction. Then I was on the ground, screaming with a rage that took even myself by surprise: "No, I'm not OK! I'm not OK! I'm not OK!"

A lot happened during the four weeks I spent at Spaulding Rehab.[1] The Red Sox won the World Series. A record number of women and minority candidates were elected to Congress. Participating in these bonds of anticipation, suspense, and elation didn't make me forget that I was wedded to my wheelchair, another kind of bond, never before contemplated and in many ways more interesting than the others. This unsightly contraption, a marvel of metallic suppleness, was never apart from me or out of my mind: not the new normal but simply part of life, taken for granted and integral to my sense of myself. Not being able to live without it defined me, an identity I got used to with surprising ease.

The motto for Spaulding Rehab is "Find Your Strength," a clear-eyed, matter-of-fact injunction that I appreciated when I arrived, and even more so when I left, still needing an ambulance. For those of us living with the unpredictable course of the injured body, strength is not a given, not a fact in the present tense.[2] Not securely lodged, it is rather an aspired-to outcome, the promise of a yet-to-be-realized future. One has to work for it, try to find it. What one finds varies greatly from one person to another. There is always the chance that the search will be in vain, that this aspired-to outcome will always remain aspired-to, beckoning from a place just beyond our reach.

This uncertain future brings to mind the taunt popularized by disability activists: "temporarily abled-bodied."[3] Most of us think

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of disabilities resulting from injury as short-term, coming to an end when we recover fully and return to normal life. These activists remind us that this might not happen, that full recovery might elude us, and that the assumption about able-bodiedness as the condition of normalcy is misguided to begin with. Robert McRuer calls it "compulsory able-bodiedness" (*Cr* 2 and *Cr* 190–92), a concept Janet Lyon discusses at some length in this issue's Theories and Methodologies section. Compulsory it might be, but this bodily norm also turns out to be sadly unenforceable over the course of a life, for a simple reason: time does not always cooperate. The trajectory that posits able-bodiedness as the end point is more honored in the breach, for time tends to go in the opposite direction, offering an entropic spiral, sending all of us to some form of disability as the baseline condition, a state of maximum likelihood.

Seen in this light, disability studies is not a minority discourse, of interest only to a small segment of the population.[4] It speaks to all of us, calling out the vulnerability inscribed in our physical embodiment, an inscription dictated by time itself. The entire human species comes together on this common ground, the broadest and most egalitarian, our age-induced weakness and general susceptibility to harm uniting us where we least want to be. These sobering prospects reveal what Donna Haraway calls a "tentacular" form of kinship (30–57),[5] linking different life-forms and permeating every activity, with far-reaching consequences for the way we conduct ourselves on earth and take stock of the many vulnerabilities now facing the planet's inhabitants.

And disability studies is not alone. Two other emerging fields, medical humanities and environmental humanities, also start from this disconcerting but necessary place, building a curriculum, a field of knowledge, and a way of life from the time-inscribed vulnerabilities of the body and gesturing toward a planetwide kinship on just this fraught footing. Tracing this development in disability studies and medical humanities before turning briefly to environmental humanities, toward the end, I try to outline a ground-level discipline, energized and unified by the hazards faced by all. Proceeding from the vulnerabilities of a single set of space and time coordinates, such a humanities is potentially extendable to all the space and time coordinates of the world, interlacing the macro and micro as no other discipline can.

I begin with Rita Charon, internist at Columbia University's Irving Medical Center, professor and chair of the Department of Medical Humanities and Ethics, and founder and executive director of the Division of Narrative Medicine at the Columbia Medical School. This division, begun in 2000, was the first in the United States to advocate an overhaul of the medical profession based on the art of close reading and "radical listening" (Charon, *Nar* ; Charon et al.). While many medical schools have welcomed the humanities—when the Penn State College of Medicine opened its doors in 1967, the department of humanities was one of its founding departments ("Humanities")—the Columbia program does so for a particular purpose. Instead of training medical students in only one method, a symptom-based approach to clinical practice, Narrative Medicine enlists the humanities to replace that approach with one attentive to the life of the patient as a whole, giving pride of place to "narrative competence," the ability to "recognize, absorb, interpret, and be moved by the stories of illness" ("About Narrative Medicine"). Since then, courses in narrative medicine have become a requirement for all four years of medical school at Columbia. In 2009 an MS in Narrative Medicine was added, opening the program to working professionals and to students from other medical schools. The University of Nevada, Reno; Temple University; and the Warren Alpert

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School of Medicine at Brown University now have similar programs (Krisberg).

In her 2018 Jefferson Lecture,[6] Charon began with the vulnerability of the human body and the unique ability of narrative to convey it. She then zeroed in on one painting, James Abbott McNeill Whistler's *Sea and Rain* (fig. 1), as a visual narrative capturing her sense that "the entire inner action of medicine is nothing but a struggle against the powers of time."[7] What especially strikes her about the painting is the tension between the delicacy of the palette and the immensity of sea and sky: the time-bound versus the timeless. Caught between these two poles is a minuscule human figure embodying both: a mere sketch, with legs either meant to be translucent or accidentally left un-filled-in. Is this figure at home in the cosmic vastness, a nontrivial spot of time in this flux and flow, momentarily having the sea and the sky all to himself? Or is he expendable, erasable, an afterthought? For Charon, there is no question more central to narrative medicine than the duality of human beings as both timeless and time-bound. Whistler's rendition of that duality is so haunting that Charon hired a painter in London to make her a copy to contemplate every day.

Still, it seems that the "narrative competence" of the physician would win out and get through to the patients' stories with no loss occasioned by the space and time intervening between these two. Sayantani DasGupta, Charon's colleague in the Division of Narrative Medicine, is not so sure. Mindful of the asymmetry between physician and patient and the fact that "each story we hear holds elements that are unfamiliar—be they cultural, socioeconomic, sexual, religious, or idiosyncratically personal," DasGupta argues that there can be no easy access to a lifeworld

Fig. 1
James Abbott McNeill Whistler, *Sea and Rain*, University of Michigan Museum of Art, Bequest of Margaret Watson Parker, 1955/1.89.

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shaped by these unfamiliar elements and that "we cannot ever claim to comprehend the totality of another's story." All we can hope to do is find some tentative "entry point," which in turn depends on recognizing that there are "larger forces" at work in each individual life, forces that "enable the telling of certain sorts of stories and silence other stories." Narrative medicine, in this sense, is never just a one-on-one conversation between patient and physician and never just a record of the latter's success in understanding the former. *Not* understanding is probably more common. DasGupta calls on the listener-interpreter to practice "narrative humility,"[8] to replace "competence" with self-acknowledged limits and become "a student again,"[9] the better to learn about the larger forces that make up the lifeworlds of patients before, during, and after the medical consultation.

More recent versions of medical humanities—programs housed in the Faculty of Arts and Sciences (FAS) rather than the medical school—have largely proceeded from this knowledge-building, limit-conscious starting point.[10] Serving a more diverse student population than physicians in training, these programs necessarily have more diverse course offerings. Furthermore, the range of expertise among faculty members teaching these courses enables FAS-based medical humanities to operate on a scale coextensive with the full range of human suffering and vulnerability, across time as well as space. This expanded scope, in turn, puts pressure on the reconfigured field as it enters into needed partnerships and runs up against new methodological challenges along the way.

The medical humanities program at Ohio State University, Columbus (OSU), is a case in point. The home of *Narrative*, the award-winning journal of the International Society for the Study of Narrative, and a related worldwide network of scholars, Project Narrative, OSU already has the on-site infrastructure to take the field forward. As with the Columbia program, the founding insight here is that "the patient is more than just a list of symptoms and test results."[11] At OSU, that insight leads to three linked initiatives operating through three institutional entities.

First, at the College of Medicine, a longitudinal elective, Literature for Physicians: From the Page to the Bedside, is co-taught by an English professor, James Phelan, and a medical doctor, Erin McConnell. Adopting an evolving syllabus and culminating in a "capstone project" that could be community work or art exhibition in lieu of a regular research paper, the course is designed to fit into the tight schedule of medical students and to prepare them for clinical practice. It meets once a month and, if necessary, can be completed over several years (Phelan, MedColl771 syllabus). The second initiative, an MA program in Medical Humanities and Social Sciences, housed in the English Department, brings a dozen FAS departments into its orbit, making literature a key feature in OSU's interdisciplinary landscape. The third initiative, an undergraduate minor taught by FAS faculty members from the natural sciences, social sciences, and humanities, is even farther-reaching. Of the five courses needed to complete the minor, the mandatory core course can come from one of four departments: classics, comparative studies, English, and history. The four electives, meanwhile, can come from anthropology, communication, health and rehabilitation science, philosophy, psychology, public health, sociology, and women's, gender, and sexuality studies—a multicentric, multilayered constellation, unlike any minor currently existing.

At OSU, the importance of classics to medical humanities is especially striking.[12] Homer, after all, is generally believed to have been blind, and no literature is more eloquent on the sexual, social, and geopolitical consequences of disabilities than the *Iliad* and the *Odyssey*. Philoctetes, banished by the Greeks in the *Iliad* because of the foul smell

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of his unhealing wound, eventually has to be brought back from exile by his suitably chastened compatriots—a story that has inspired poets and playwrights from Euripides and Sophocles to André Gide, Seamus Heaney, Adrienne Rich, and Derek Walcott. And vulnerability is by no means reserved for mortals alone. Hephaestus, divine blacksmith, was born lame and was thrown off Mount Olympus by his mother, Hera, for that reason, only to survive and become the husband of Aphrodite, enduring a marital bond as indissoluble as it is tormenting. The Homeric epics are full of wounds both physical and not. Among their unforgettable cast of characters, a crippled god and a human being with a festering wound might turn out to be two of the most resonant emblems for the harm-rich twenty-first century.

Disability studies as a field both ancient and modern goes hand in hand with medical humanities, each spanning a broad swath of space and time while remaining anchored in the exigencies of the here and now. At OSU, the partnership between these two has come into focus, most notably in the 2017 conference Narrative, Medicine, Rhetoric, Disability, featuring keynotes by Michael Montoya and Ann Fox. Montoya, a scholar-advocate with joint appointments in anthropology, Chicano/Latino studies, nursing, and public health, as well as medicine, gave a talk titled "Making and Unmaking the Mexican Diabetic: Out of the Lab, into the Streets, and Home Again." Fox, a disability studies scholar long committed to public-facing work on *YouTube* ("Imagining"), in MOOCs ("Ann M. Fox"), and in art exhibitions (most recently *Graphic Medicine*), spoke on "adaptive activism," a discussion of "why collaboration through disability representation matters" ("Adaptive Activism"). Hosting these two scholars and in part speaking through them, the 2017 conference brought together medical humanities and disability studies by highlighting the advocacy integral to both, making coalition building and crisis responsiveness procedural outcomes in scholarly endeavors.

In all these ways, the OSU program seems agenda-setting, inviting affirmation, dissent, and further innovation from other universities. Its counterpart at the University of North Carolina, Chapel Hill (UNC), is an especially interesting variation. Anchored by HHIVE (Health Humanities: An Interdisciplinary Venue for Exploration), this program features a two-pronged initiative: an MA in Literature, Medicine, and Culture, housed in the Department of English and Comparative Literature, and an undergraduate minor, housed in the honors program. Calling itself "Health Humanities" rather than "Medical Humanities" but not insisting on this as an absolute distinction,[13] the UNC program shifts the focus away from training for physicians to building a curriculum reflecting the full range of knowledge from across the FAS, as well as the Medical School and its allied schools of nursing, social work, and social medicine. What results is a correspondingly broad landscape of health care, foregrounding the work of caregivers other than the physician, as well as the limits of medicine, not least when it comes to terms with the death of the patient.

ENGL 268, Literature, Medicine, and Culture, a large lecture course taught alternately by Jane Thrailkill and Matthew Taylor, devotes its final week to end-of-life care, featuring the voices of patients (in this case, Raymond Carver's, in the poems "What the Doctor Said" and "My Death"), along with meditations by doctors (such as Atul Gawande's "Letting Go: What Should Medicine Do When It Can't Save Your Life?").[14] Is mortality an insurmountable challenge to medicine, dooming it to failure, or is it an integral part of medicine, making it a humbler undertaking, to be judged not by its unfailing ability to cure but by a procedure more complex and equally important to the well-being of the patient, something like the steadfast availability of care whenever needed?

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This emphasis on care, rather than cure, brings into play a large number of caregivers, some professional and others moved by familial obligations and personal loyalties.[15] At UNC, the presence of the School of Nursing gives its Health Humanities a distinctive flavor. The fall 2018 issue of its *Health Humanities Journal*, a student-run publication, the first of its kind, opens with a poem, "To the patient in the blue gown in room 74." The author, Terra Scarlette Beek, a nursing student, chronicles a flurry of activities in a hospital room, climaxing in a "*danse macabre*," an attempt to revive "a lifeless body," and then subsiding when the patient fails to come around:

> And now
> And now, there is silence.
> The soft "beep, beep" drags on but the *danse*
> is over.
>
> Purple manicured nails rest easily on a bed
> rail,
> A weary mother caresses a cheek.
>
> To the patient in the blue gown in room 74—
> *Did you know today would be the day*
> *You would learn to live again?*

For someone training to become a nurse, death is nothing out of the ordinary. The patient is shown here not in her death throes but at peace, her manicured nails resting on the bed rail and her cheek caressed by her mother. The fact that the patient is a daughter outlived by her mother hints at a potentially worrisome generational reversal, but any worry is offset by the unexpected reassurance at the end that, in death, one "learn[s] to live again." What could that possibly mean? That sense of perpetual beginning—and perpetual learning—arguably has less to do with renewed life for the patient than with renewed work for the nurse as new patients cycle through. Caregiving is everywhere needed, and everywhere interminable, a life force to those who offer it no less than to those who receive it. It is the stuff poetry is made of.

Health Humanities is enlarged by this sense of poetry, as it is enlarged by the number of people inspired to think of themselves as poets.[16] The macro and the micro are mutually reinforcing here, which is also generally true of much else in this broad-based program, effectively constituting itself as a global field despite its dedicated focus on bodily vulnerabilities. Even though the lecture course ENGL 268 sees medicine and culture largely through an Anglo-American lens, it is more than complemented by allied FAS courses ranging from those on global health care and comparative health care, offered by the anthropology department, to those on the geography of health care delivery and on geographic information systems in public health, offered by the geography department. Health-care systems around the world tell us a great deal about the world order even as they make themselves felt as granular details in individual lives. The UNC program is committed to exploring both.

Can health humanities lead to a planetwide kinship, something like the "species thinking" urged by Dipesh Chakrabarty—a sense of common vulnerability and responsibility shared by all humankind, newly aware of itself as an endangered species, "a form of life" taking its place among the "history of life" on the planet (213)? I'd like to conclude by looking briefly at a course that does gesture in that direction, Case Studies in the Medical Humanities: Interdisciplinary Perspectives on the Experience of Illness and Healing, a large lecture course offered under the Program in General Education (Gen Ed) at Harvard University.

Gen Ed, "at the heart of the intellectually transformative mission of Harvard College," is meant to "help students to understand the deep relationship of scholarly work to some of the most important aspects of life beyond college" ("Program"). Medical humanities is ideal for those purposes. The course Culture and Belief 58, for instance, is taught by three faculty members: David Jones, a medical doctor from the Department of Global Health

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and Social Medicine; Arthur Kleinman, with appointments in the Department of Anthropology and the Medical School; and Karen Thornber, Director of the Asia Center and a professor in the Departments of Comparative Literature and East Asian Languages and Civilizations.[17] Given the non-Western research focus of these three scholars,[18] medical humanities has an entirely different meaning in their course. "Taking medicine beyond the clinic" is not a polemic but a pursuable goal, a section of the syllabus that takes the course from family caregiving to the rise of social medicine, featuring an interview with Paul Farmer, cofounder of Partners in Health, the NGO known for its work beyond the clinic in Haiti (Thornber, CB 58 syllabus).

But even this is just the tip of the iceberg. Caregiving is a phenomenon broader than the medical profession itself. There is no reason why it should be limited to just one sphere of life or one kind of recipient, especially in the twenty-first century, when healing is required on so many fronts. The syllabus of Culture and Belief 58 is explicit on this point. The ultimate goal of the course is to "consider caregiving at different scales, from the traditional focus on patient-doctor relationships to emergent concerns with climate change and planetary health." Through its wide-ranging exploration of "suffering and resilience," the course invites students to rethink "what it means to be human." To do so, at this level of synthesis between the macro and the micro, is to put the collective future of this endangered species squarely on the table, holding it accountable for the ills it has inflicted on its habitat and on itself and making a new politics, a new democracy of care, the condition for its survival.[19] On this point, disability studies, medical humanities, and environmental humanities speak with one voice.

Wai Chee Dimock

Notes

1. I was admitted to Mount Auburn Hospital on 11 October 2018 and to Spaulding Nursing and Therapy Center on 15 October, with a dislocated right shoulder and fractured left knee. At the moment of writing, in January 2019, my leg is once again weight-bearing, though the shoulder has been reinjured.

2. *Vulnerability* is emerging as a key term in social psychology (Brown, "Power" and "How Vulnerability Can Make Our Lives Better").

3. See especially Davis; Garland-Thomson; Kafer; Linton.

4. According to the United Nations, "around 10 per cent of the world's population, or 650 million people, live with a disability. They are the world's largest minority" ("Fact Sheet"). In response to complaints from Apple, the 2019 official Unicode list of emojis now contains dozens of accessibility-related images, including wheelchairs, hearing aids, prosthetic limbs, probing canes, and guide dogs. They will appear on smartphones in the second half of the year ("Disability-Themed Emojis").

5. Haraway is speaking specifically of an interspecies kinship, but "tentacular" seems to me also a good description of an all-permeating kinship among human beings.

6. The Jefferson Lecture is the "highest honor the federal government bestows for distinguished intellectual achievement in the humanities" ("Dr. Rita Charon").

7. As Charon explains, this is a paraphrase of Georg Lukács ("2018 Jefferson Lecture").

8. DasGupta here draws on the work of Tervalon and Murray-Garcia, who proposed using the term "cultural humility," rather than "cultural competence," to define an essential component of training for multicultural clinical practice.

9. DasGupta is quoting from Broyard.

10. Medical humanities programs are housed in medical schools at Baylor University; Emory University; the University of Mississippi; Northwestern University; the University of Texas, Galveston; Vanderbilt University; and Yale University. Outside of medical schools, broadly interdisciplinary literature-and-medicine programs are housed in the FAS at, among other universities, Arizona State University; Boston College; the University of Washington, Seattle; the University of Oregon; and the University of North Carolina, Chapel Hill. In the United Kingdom, Bristol University; Durham University; Leicester University, Birkbeck; the University of London; King's College London; and the University of Swansea all have medical humanities programs.

11. The project was awarded $130,000 in funding from the university, enhanced by $24,000 from an individual donor (Phelan, E-mail).

12. In addition to offering one of the four options for the core course, the classics played a vital role in the 2018 conference hosted by OSU's Humanities in Medicine,

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which featured a keynote address by Brooke Holmes, professor of classics at Princeton University.

13. Others have been more emphatic about the distinction. See especially Crawford et al.; Jones et al.; Klugman.

14. "Letting Go," originally published in *The New Yorker*, is now a chapter in Gawande's best-selling book *Being Mortal*. Gawande belongs to a long tradition of physicians who are also distinguished writers, including Oliver Sacks and Rafael Campo.

15. Disability studies has been especially eloquent in critiquing the orthodoxy of cure. See Janet Lyon's essay in this issue's Theories and Methodologies section.

16. The ability of poetry to reach patients with dementia is well documented. See, e.g., "Poetry Project."

17. This course was offered in fall 2017, with a special emphasis on caregiving. A new version of Gen Ed will be implemented in fall 2019.

18. See D. S. Jones; Akyeampong et al.; Thornber, *Ecoambiguity*.

19. I am responding here to Purdy's call for a "politics for the Anthropocene."

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