The Almost Right Word: The Move From Medical to Health Humanities
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Abstract
Since the emergence of the field in the 1970s, several trends have begun to challenge the original assumptions, claims, and practices of what became known as the medical humanities. In this article, the authors make the case for the health humanities as a more encompassing label because it captures recent theoretical and pedagogical developments in higher education such as the shift from rigid disciplinary boundaries to multi- and interdisciplinary inquiry, which has transformed humanities curricula in health professions. Calling the area of study health humanities also underscores the crucial distinction between medicine and health. Following a brief history of the field and the rationales that brought humanities disciplines to medical education in the first place—the “why” of the medical humanities—the authors turn to the “why” of the health humanities, using disability studies to illuminate those methodologies and materials that represent the distinction between the two. In addition, the authors make note of how humanities inquiry has now expanded across the landscape of other health professions curricula; how there is both awareness and evidence that medicine is only a minor determinant of health in human populations alongside social and cultural factors; and finally, how the current movement in health professions education is towards interdisciplinary and interprofessional learning experiences for students.

The difference between the almost right word and the right word is really a large matter—it’s the difference between the lightning bug and the lightning.
—Mark Twain, Letter to George Bainton, October 15, 1888

[Words] deserve respect. If you get the right ones in the right order, you can nudge the world a little.
—Tom Wolfe, The Right Stuff

In conversation with a clinical colleague, one of us attempted to explain the difference between medical humanities and health humanities, the latter a term used with increasing frequency in health professions education as well as undergraduate settings. She cited a common complaint among many health care professionals, that the word “medical” denotes just that: medicine—not dentistry, not nursing, not pharmacy, not physical or occupational therapy. She also pointed out that the focus, content, and goals of medical and health humanities are sometimes different and offered specific examples. Her colleague listened intently for a while and then smiled, as he said, “Oh, the things you academics worry about….”

As anyone who has deliberately used the word adherence instead of compliance knows (and wondered whether the intentional rhetorical shift really avoided infantilizing patients), clinicians also worry about semantics. Academics may simply be the “first responders,” those who bring problematic words and contested meanings to clinicians’ attention. Humanities scholars in health professions education are not just splitting hairs with this “worrying” about word choice. Rather, we are attentive to precision in language as it relates to the ethical dimensions of why, what, and how we teach and to whom our efforts are directed. Medical humanities remains an appropriate phrase to describe the work done by scholars and educators, often but not limited to medical schools, whose focus is on the intersection of medical phenomena (e.g., physicians, patients, illness) and the traditional disciplines of the humanities including history, literature, philosophy, and visual arts. However, since the emergence of the field in the 1970s, several trends have begun to challenge the original assumptions, claims, and practices of what became known as the medical humanities.

In this article, we will make the case for the health humanities as a more encompassing label because it accurately captures theoretical and pedagogical developments in higher education as well as health professions education. To that end, we will discuss in detail the shift from rigid disciplinary boundaries to multi- and interdisciplinary inquiry across the academy and how that has transformed humanities curricula in health professions education. To begin, we provide a brief history of the field and the early rationales that brought humanities disciplines to medical education in the first place—the “why” of the medical humanities. Following this history, we organize our discussion on the “why” of the health humanities using disabilities studies to illuminate those methodologies and materials that represent, in our view, the distinction between medical and health humanities.

The Why of Medical Humanities: Historical Perspective

It was not mere chance that brought humanities disciplines into the medical curriculum over 40 years ago. Seemingly miraculous but morally troubling medical
advances such as organ transplantation, reproductive technologies, new genetics research, and shifting standards of death made it clear that the traditional curriculum was not yet up to the task of addressing complex human and ethical issues. During the decade of the 1970s, a number of now foundational books were published in reaction to the increasing power of Western biomedicine over the patient, often raising concerns about excessive paternalism and always advocating for patient autonomy. Titles included Ivan Illich’s Medical Nemesis (1976), Susan Sontag’s Illness as Metaphor (1978), Norman Cousin’s Anatomy of an Illness (1979), and Tom Beauchamp and James Childress’ Principles of Biomedical Ethics (1979), now in its seventh edition. Also influential were patients’ rights manifestos such as the groundbreaking Our Bodies, Our Selves (1972) by the Boston Women’s Health Collective and Let Me Die (1975), the classic documentary film about Dax Cowart, hospitalized for severe burns and treated against his will.

Moreover, it wasn’t only intellectuals, academicians, and activists who were calling for a cultural transformation that would address the imbalance between the technological aspects of medicine and the human facets of health and caregiving. In the inaugural session of the Institute on Human Values in Medicine in 1972, physician and bioethicist Edmund Pellegrino challenged participants to “bring some of us in medicine who are concerned with issues involving human values into close discourse with those … in the disciplines outside of medicine who have interest in, and perhaps a desire to help us with, the human problems that arise in medicine for the patient and the physicians.” In those same proceedings, K. Danner Clouser’s call to action would not only motivate listeners to go forth and develop programs but would also predict how the medical humanities were enacted in decades to come:

However, Clouser’s pronouncement—“each from its own perspective, methods, and resources”—did not result in programs with common goals or similarly credentialed faculty who employed like methods and resources. For instance, some were simply called “programs”—while others became centers, departments, divisions, or offices. Some schools offered electives; others embedded humanities content in larger courses such as “Physician, Patient, and Society” and “Doctoring” or in longitudinal sessions threaded throughout the curriculum.

Still, the field and its practitioners grew. In 1972, the Institute on Human Values reported 11 “teaching programs in human values” in medicine; today, well over 60% of medical schools report both required and elective humanities courses. In 1973, the Institute for the Medical Humanities at the University of Texas Medical Branch at Galveston further advanced the field by implementing the first graduate degree programs in medical humanities; today, nearly 50 colleges and universities in the United States offer an undergraduate major or minor, and the number of graduate programs in both medical humanities and narrative medicine is on the rise.4

A number of other benchmarks chart the successful expansion and advancement of the field, including the publication of several peer-reviewed journals such as the Journal of Medicine and Philosophy (1976), Journal of Medical Humanities (1980), Literature and Medicine (1982), and Medical Humanities (2000). The most prominent professional organization, the Society for Health and Human Values, founded in 1968, merged with two bioethics organizations in 1998 to become the American Society for Bioethics and Humanities. Finally, there are numerous conferences and meetings nationally and internationally as well as vibrant listservs, blogs, databases, and other networks.

So, why would anyone want to change the designation of a field that has matured to this extent? Below, we will argue why this change is needed from the perspective of those in the health professions who use the humanities and through both the pedagogy and content of an emergent health humanities.

The Why of Health Humanities

As described above, humanities inquiry took hold and gained prominence in medical education more so than in other health professions curricula. This is reflected, for instance, in the titles of the major journals in the field. But even as humanities inquiry began to thrive across the landscape of health professions education, the term medical stuck: not nursing humanities, not physical therapy or occupational therapy humanities, even though their respective domains of knowledge, spheres of practice, and relationships with patients are distinctive and essential to health care.

In their recent book, Health Humanities (2015), Paul Crawford and colleagues noted that “not everyone aligns with medical visions of healthcare…. There are multiple and often complementary contributions to health and well-being which fall outside medicine per se.” In fact, the terminological shift from medical to health humanities underscores the crucial distinction between medicine and health. As epidemiological evidence shows, medicine is only a minor determinant of health in human populations alongside other social factors such as class, education, occupation, environment, race, and stigma. Crawford et al also provided one of the earliest recognitions of this theoretical shift in the field, prompting scholars to argue for “a more inclusive, outward-facing and applied discipline” that “embrace[s] interdisciplinarity and engage[s] with the contributions of those marginalized from the medical humanities—for example, allied health professionals, nurses, patients and carers.” Such a call is consistent with the current movement in health professions education toward crafting interdisciplinary and interprofessional experiences for students whenever and wherever possible, from classroom discussions to clinical rotations.

Moreover, when the humanities began to appear in medical education, the disciplinary boundaries were still relatively intact, so that classes titled “Literature and Medicine,” “History of Medicine,” and “Philosophy and Medicine” were fairly routine and increasingly familiar offerings in the curriculum. But when the larger academy began to mirror the profound
cultural and global changes of the last quarter of the 20th century, multiple area studies—all multidisciplinary and interdisciplinary—began to emerge, focusing more pointedly on issues surrounding race, gender, sexual identities, embodiment, and cultural origins. These included, for example, women’s studies, disability studies, postcolonial studies, and queer studies, and it was not long before these began to influence medical education. A course offered 25 years ago as “Literature and Medicine” may have been replaced by “Women’s Bodies and Health in Literature,” or “Law and Medicine” replaced by “Women, Reproduction, and Power.” The former, taught by one of us (D.W.), is an inquiry into representations of women’s bodies throughout history in literature, film, popular culture, and medicine; the latter is an examination of reproductive rights in law and medicine. Other courses we currently teach include “HIV/AIDS and American Culture” (T.J.), “Perils of the Normal” (M.B.), and “Representations of the Nurse in Literature, Film, and Television” (R.G.). None relies on canonical knowledge that resides in a single discipline, such as history or literature, and none is particularly interested in physicians themselves. Rather, most are far more concerned with individual and cultural experiences of illness and disability and with the social/structural/political impediments to health and healing.

In addition, the theory of intersectionality is key to health humanities inquiry. Similar to how the shift from medical humanities to health humanities marked a movement away from rigid disciplinary boundaries to multidisciplinary or interdisciplinary inquiry, intersectionality is a way of thinking about identity and its relationship to power. In particular, intersectionality brings to bear how different types of disadvantage interact, or as the Oxford Dictionary defines it: “the interconnected nature of social categorizations such as race, class, ability, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage.”6 First coined by legal scholar Kimberlé Crenshaw,7 the term is a reminder that there are no homogenous categories of humans.

Intersectionality is a particularly useful theory in medicine where categories are ubiquitous (e.g., boxes to tick on the EMR) yet rarely explored at their intersections. For instance, one can speak globally about “men’s health” but not consider the intersection of race, class, gender identity, ability, religion, national origins, or immigration status as they factor generally into men’s health or as they factor into a particular man sitting before us. Similarly, one can talk about “urban medicine” but fail to understand the differing experiences of a disabled person living in an urban setting versus that person living in a rural setting—the intersectionality is more powerful than either descriptor/demographic alone. In fact, disability studies offer a particularly cogent example of a health humanities orientation in the medical curriculum.

Disability Studies and Health Humanities

Disability studies seeks to problematize prevailing views of the body and mind in part by drawing distinctions between a medical and social model of disability and by extension, disease, health, and well-being. Where medicine most often locates disability in the individual, the social model locates it in the world, or rather in the interface between atypical bodies and minds and the social and physical environment. In short, medicine medicalizes disability; disability studies diverts attention away from medicine, not to disavow its importance but to draw attention to other areas contributing to disability. Thus, disability is produced by discrimination and barriers that prevent persons with impairments from gaining access to social and political as well as physical spaces: “While individuals have impairments (differences of function), disability is not located in those individuals but in the interactions between people and their social and physical environments, which jointly produce ability and disability by degrees.”8 For Lennard Davis,9 a leader in the field of disability studies, “the clearest example of this distinction is seen in the case of wheelchair users. They have impairments that limit mobility, but are not disabled unless they are in environments without ramps, lifts, and automatic doors.” Disability studies asks us to shift our attention away from an exclusive focus on fixing individual bodies perceived as broken (the medical model) to fixing attitudes and environments that exclude certain kinds of bodies and minds (the social model).

Informed by and acting on the insights of disability studies, the health humanities offers students and practitioners access to a distinctive point of view about experiences of illness and impairment that may, in turn, change how providers, especially physicians, view patients. G. Thomas Couser10 provides one example of the improvements in care that become possible as a consequence of this perspective shift:

One often hears disabled people referred to as “suffering from” X. Sometimes this is the case, of course, but conditions that are inherently painful or causes of constant suffering are rarer than many think. The phrase is really a speech formula that assigns or presumes suffering in the absence of testimony. More important, many disabled people claim that they suffer more from stigma, marginalization, and exclusion of disability than they do from their impairment itself.

By no longer presuming that individuals suffer from their impairments, health care providers can address the actual lived experiences of patients and more likely improve their overall health and well-being. Like the larger field of health humanities, disability studies are interested in subjective experiences for a more nuanced and accurate understanding of the quality of life lived with a disability11 and an expanded imagination regarding that life.12 As such, health humanities courses consistently include past and present examples of life writing about bodies made unusual by illness or impairment.

Media and Messages

This leads to our final point, which is that health humanities content cannot be separated from its form. Because of the shift in exploring health and illness with a wider lens, health humanities curricula are far more inclusive in where content is found and how it appears. In addition to the usual fare of short stories, novels, poetry, narrative nonfiction, historical accounts, and bioethics case studies, health humanities courses routinely include film, particularly shorts and patient- or family-made videos; blogs; discussion forums; Web sites; and listservs focusing on experiences of illness and trauma, along with information sharing. Graphic novels and comics are particularly useful
in helping readers (and here, health care providers) make inferences because the format relies on pictures and small amounts of text.

**Concluding Remarks**

Medical educators should care about the name change because the expanded role of the humanities across the curriculum focuses no longer merely on doctors or on the clinical aspects of disease and impairment but also on all health professionals and on the experience of illness and disability. Moreover, humanities approaches have the capacity to remind our students that medicine is but one component of health and well-being and that their patients will come to them with a broader set of expectations and needs.

If not the best word—from medical to health humanities—then we will just have to settle for the “almost right word” at this time.

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**References**


