

# Introducing Medical Humanities

*Of the physician's character, the chief quality is humanity, the sensibility of heart which makes us feel for the distress of our fellow-creatures.*<sup>1</sup>

– John Gregory

## INTRODUCTION

“I had undergone three heart surgeries in two years,” Dr. Steven Hsi writes, “numerous tests, dozens of visits to doctors’ offices, extended stays in hospitals and long recuperative periods at home.”<sup>2</sup> He continues:

I was 43 years old, a successful physician, married to a wonderful woman and blessed with two fine sons – all of it assaulted by a rare heart disease of such catastrophic power that it did more than threaten my life. It nearly destroyed my family.<sup>3</sup>

Dr. Hsi and his family coped well enough, he writes, but no one, especially none of his doctors, asked him what he felt to be the most important questions: “What has this disease done to your life? What has it done to your family? What has it done to your work? What has it done to your spirit?”<sup>4</sup> “Regardless of the considerable compassion and caring of many of them,” Dr. Hsi concludes, “no one asked the questions that needed to be asked. I have come to believe this oversight was the single most grievous mistake my doctors made.”<sup>5</sup> Existential questions – questions about the meaning of life and death – are essential to medicine. This book is designed to help you engage the most important questions.

During the last fifty years, health care professionals have struggled with dehumanizing tendencies created by the unprecedented success of modern medicine and the commercialization of the health care system – not enough time to see patients; technology that shifts attention to machines rather than patients; growing incentives to put profits above patients; a biomedical reductionism that attends to pain but not suffering and to disease but not illness; and institutional cultures that undermine the health of physicians, students, and others who work

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in academic health centers.<sup>6</sup> Progress in biomedicine has also generated a great deal of moral uncertainty and ethical conflict. Since the 1960s, the new fields of bioethics and medical humanities have grappled with problematic issues such as the protection of research subjects, the goals of health care, the definition of death, the rights of patients, the cessation of treatment, the meaning of illness, and the distribution of health care resources.<sup>7</sup> Most of these topics lie within the purview of bioethics, which emerged as a field alongside medical humanities and was perhaps indistinguishable from it at first. Indeed, medical humanities considers and addresses many of the ethical problems addressed by bioethics and in some ways overlaps with bioethics.<sup>8</sup> However, medical humanities tends to focus not on the practical resolution of ethical problems but on their cultural and historical contexts, emotional and existential dimensions, and literary and artistic representations.<sup>9</sup> Medical humanities is also closely linked to newer reforms in medical education that address the erosion of public trust and the impersonal quality of relationships between patients and health care professionals. These efforts focus on, for example, professionalism, the renewal of spirituality, relationship centered care, cultural competence, and narrative medicine.<sup>10</sup> Each of these fields or movements seeks to address the dehumanization of medicine – experiences such as Dr. Hsi’s – in one way or another; medical humanities is the most intellectually comprehensive of them.

While we offer our own definition of and vision for medical humanities below, perhaps it is best to begin by defining not medical humanities but the humanities more broadly. What are the humanities? Why do they matter? And how did they come to be engaged with medicine and health care?

DEFINING THE HUMANITIES

What we now call the humanities first emerged during the fifth century BCE in ancient Greece, when teachers of rhetoric focused on preparing free men to participate in democratic deliberation, which required mastery of the arts of language rather than the art of war. Then, as now, success in the public realm required the capacity for rational argumentation and persuasion.

The word “humanities” derives from the Latin word *humanitas*. Originally, *humanitas* – in English “humanity” – meant humane feeling, which today could be known variously as sympathy, empathy, compassion, pity, concern, or caring. It was also understood as a kind of virtue inspired by knowledge or a quality of refinement achieved by intellectual accomplishment. *Humanitas* in this sense was similar to the Greek term *philanthropia*, that generous spirit toward others that ideally results from education in the liberal arts. In the fourteenth-century Italian Renaissance, Petrarch (1304–1374 CE) rediscovered the term *humanitas* from Cicero (104–43 BCE) and shaped it into the ideal of forming a person who combines humane feeling with liberal learning and action in the

world.<sup>11</sup> This threefold ideal was built into the tradition of liberal education in the United States and reformulated by Lionel Trilling (1905–1975) as the “humanistic educational ideal”<sup>12</sup> in the 1970s, when it first came under severe criticism from postmodernist thinkers. The humanistic educational ideal can be seen in strong form today, for example, in the work of Martha Nussbaum (1947–).<sup>13</sup> For all its limitations, we support this ideal, which is wholistic, fluid, and individual. This bears repeating: humanistic education aims at forming a whole person who is compassionate, knowledgeable, and who acts in the world. It aims to educate the emotions as well as the intellect, to enhance compassion as well as critical thinking, and to encourage active engagement in public and/or professional life.

Defining the humanities today is not a simple task. They can be defined by subject matter, disciplines, or methods, but no final definition is possible or perhaps even desirable. Defined by its subject matter, the humanities reflect on the fundamental question, “What does it mean to be human?” As the Rockefeller Commission on the Humanities put it in 1980: The humanities “reveal how people have tried to make moral, spiritual, and intellectual sense of a world in which irrationality, despair, loneliness, and death are as conspicuous as birth, friendship, hope, and reason. We learn how individuals or societies define the moral life and try to attain it, attempt to reconcile freedom and the responsibilities of citizenship, and express themselves artistically.”<sup>14</sup> Defined by disciplines, the humanities range from languages, literature, history, and philosophy to religious studies, jurisprudence, and those aspects of the social sciences (in particular anthropology, sociology, and psychology) that emphasize interpreting, valuing, and self-knowing. Defined by their methods, the humanities have been delineated by Ronald S. Crane (1886–1967) as the cultivation of four essential “arts: language, analysis of ideas, literary and artistic criticism, and historiography.”<sup>15</sup> Rather than mathematical proof or reproducible results (i.e., scientific ways of knowing), humanities scholarship and education are dedicated to understanding human experience through the disciplined development of insight, perspective, critical understanding, discernment, and creativity. Still it seems that disciplines, subject matter, and methods – whether taken separately or together – cannot adequately characterize the humanities because the humanities ultimately emphasize description, interpretation, explanation, and appreciation of the variety, uniqueness, complexity, originality, and unpredictability of human beings striving to know – and to change – themselves and their world.

Since the 1960s, a cascade of new intellectual movements and projects has broadened the scope of the humanities beyond its traditional boundaries to include what Cathy Davidson and David Goldberg call “interdisciplinary humanities”<sup>16</sup> (e.g., ethnic studies; age studies; gender studies; disability studies; cultural studies; media studies; science, technology, and information studies; and global studies). Medical humanities, and its emerging sibling health humanities,

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are among these interdisciplinary forms of study called into being by social needs and problems that cannot be adequately addressed within the boundaries set by traditional disciplines and/or methods.

THE ORIGINS OF MEDICAL HUMANITIES

Before the late nineteenth century, there were no great research universities or medical schools in the United States. Learned physicians were trained at European universities and were steeped in the classical tradition of humanistic education. Medical students in London, Edinburgh, Paris, Padua, and Vienna had to be well versed in Greek, Latin, and the classical liberal arts and were required to read the works of Galen (131–201) and Hippocrates (460–377 BCE), among other predecessors, in Latin. History – knowledge of and identification with medicine’s vision of its past – was a central dimension of their professional identity and authority.<sup>17</sup>

Over the centuries, what we now call the humanities became more specialized and focused on pure scholarship, increasingly divorced from the life of feelings and of moral and public engagement. In the second half of the nineteenth century, this tendency toward pure scholarship was powerfully accelerated by German research universities, which emerged as the exemplar of specialized research in all areas of the arts and sciences. The dynamism and growth of knowledge embedded in the ethos of science replaced the preservation and transmission of tradition inherent in classically based education.

At the end of the nineteenth century, as more and more American medical students and physicians traveled to Germany to study in experimental laboratories and to learn about clinical specialties, biomedical science was rapidly displacing the old humanistic medicine as a source of identity and authority. When enthusiasts brought back the German model to new university medical schools in the United States, some began to advocate a new vision of medicine as an *exact* science. Yet when Johns Hopkins University Medical School (based on the German model) opened its doors in 1893, its most ardent advocates worried about excessive specialization, reductionistic thinking, commercialism, and moral drift. They worried, in other words, about the dehumanization of medicine. So it might be argued that medical humanities has its origin here, when men like William Osler (1849–1919) and John Shaw Billings (1838–1913) looked for a way of preventing science and business from taking the “soul” out of medicine. Indeed, Osler both embodied and articulated the holistic ideal of *humanitas* or humanistic education. For him, medicine was an art as well as a science; it was a calling rather than a business and required education of the heart as well as the head.

When neurosurgeon Harvey Cushing (1869–1939) spoke at the dedication of the first American professorship in the history of medicine at Johns Hopkins

in 1929, he yearned for an idealized medical culture that was irrevocably lost: “Medicine has become so scattered and subdivided,” he declared, “that there is a crying need for someone to lead it from the wilderness and bind it together.”<sup>18</sup> Osler, Billings, Cushing, and others looked to history as the key to the revival of humane and morally centered medicine. This form of historically based medical humanism (which has its contemporary adherents<sup>19</sup>) had both strengths and weaknesses. On the one hand, its strength derived from its emphasis on cultivation – the learned education and identity formation of humane physicians. On the other hand, it was limited by a white, male, upper class exclusivity: there was no room for women, Jews, African Americans, or other minorities. In addition, the Oslerian “great man” version of medical history had no awareness of the multiple ways that the history of medicine can be told. Judged by the standards of contemporary scholarship, it was insufficiently critical and self-critical and was based as much on nostalgia as on the search for historical truth.

There is also a fascinating twist in the recent history of the humanities in general and the history of medical humanities in particular. At the same time that a historically minded medical humanism was developing in medical schools in response to the dehumanization of medicine, the humanities located in colleges and universities were distancing themselves from the tradition of Western humanism. Beginning in the 1960s, professional academics in the humanities largely severed their connection to the ancient tradition of *humanitas*. By and large, the mainstream professoriate distanced itself from ideals of individual cultivation and civic engagement. Indeed, some took the tradition of Western humanism itself to task, as they came to see the humanist tradition as the product of “dead white men” who had enjoyed privileged lives, ignored questions of power, and neglected issues of race, gender, and class (and, more recently, age and sexual orientation). They argued that the ideas, images, and concepts from the humanist tradition were little more than tools used to justify the domination of white European (and American) males over colonized populations, women, and people of color.<sup>20</sup>

Ironically, medical humanities in its current form began to take shape in the late 1960s and 1970s at precisely the time when university scholars in the humanities disciplines were distancing themselves from the term humanism and the curriculum of “great books” of the Western tradition.<sup>21</sup> The most prolific and influential proponent of medical humanism in this period was Edmund Pellegrino (1920–2013), a physician-reformer who chaired the Institute on Human Values in Medicine and later became president of Catholic University, and eventually served as chair of the President’s Council on Bioethics.

In a paper delivered in 1976, Pellegrino noted that the term humanism had become slippery and difficult to define. Nevertheless, he pointed out, in some circles medical humanism had achieved the status of a “salvation theme,” meant to absolve modern medicine of its “sins.” The list of “sins” Pellegrino noted was

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a long but valuable specification of problems usually lumped together under the rubric of dehumanization: “overspecialization; technical; overprofessionalization; insensitivity to personal and sociocultural values; too narrow a construal of the doctor’s role; too much science; not enough liberal arts; not enough behavioral science; too much economic incentive; a ‘trade school’ mentality; insensitivity to the poor and socially disadvantaged; overmedicalization of everyday life; inhumane treatment of medical students; overwork by house staff; deficiencies in verbal and nonverbal communication.”<sup>22</sup> As a Roman Catholic, Pellegrino was mocking the salvific tendency among enthusiasts of medical humanism, and he articulated more modest goals: “Medical humanism is really a plea to look more closely at what medicine *should be*, and increasingly *seems not to be*. It encapsulates a pervasive ambivalence felt by even the most ardent devotees of modern medicine: Can we balance the promises of medical technology against the threats it poses to persons and societies? ... [Human beings] have always sensed that the more tools they forged and the more machines they built, the more they were forced to know, to love, and to serve these devices.”<sup>23</sup> Pellegrino realized that the classical humanist training of Osler and his forbears was gone forever. So it was best, he thought, to abandon the attempt to make every physician “a Renaissance man.” Instead, Pellegrino outlined three essential goals for the humanities in medicine (the term “medical humanities” did not come into widespread use until the 1980s and 1990s). First, the humanities would help clarify the ethical issues and values at stake in clinical decisions (through his efforts at the Institute on Human Values in Medicine, Pellegrino played a major role in establishing bioethics in the 1980s.) Second, the humanities would inculcate habits of critical self-examination. And third, the humanities would “confer those attitudes which distinguish the educated from the merely trained [professional].”<sup>24</sup> From Pellegrino’s list and language of goals for the humanities in medicine, we can see that his vision contained much of the *humanitas* ideal (a personal integration of knowledge, compassion, and action in the world), expanded somewhat beyond the gentlemanly version of medical humanists in Osler’s generation. What was new in Pellegrino’s vision of humanistic education in medicine was his recognition of the need for scholarship and guidance from scholars trained in the disciplines of the humanities.

THE TERM “MEDICAL HUMANITIES”: DEBATES AND PROBLEMS

The field of medical humanities can be conceptualized, theorized, defined, and debated indefinitely. We offer here a few of the major ways of thinking about the field as well as our own definition that will guide our presentation of and approach to the topics covered in this book.



A Field or Discipline?

Medical humanities, as noted, draws on many disciplines, including history, literature, philosophy, religion, anthropology, sociology, and other arts and sciences. One area of debate is whether medical humanities is a field or a discipline,<sup>25</sup> and whether it is multidisciplinary (i.e., uses various disciplines and approaches, *separately*, to examine a topic) or interdisciplinary (i.e., uses various disciplines and approaches that are *integrated* in some way to produce a new form of knowledge).<sup>26</sup> Our own position is that medical humanities is a field, not a discipline, and is both multidisciplinary and interdisciplinary. These distinctions and debates are important and helpful, but the key point is that medical humanities draws from many disciplines to examine issues related to the development and practice of medicine and health care. In this sense, it is similar to other fields such as religious studies or gender studies that utilize various disciplines and methods to study a subject such as religion or gender. What is different, however, is that medical humanities, unlike many other academic fields, has an essential practical component because all medical humanities knowledge carries implications for the care of patients, the professional development of students, the continuing education of residents and physicians, and/or the health of populations.<sup>27</sup>

The Problem of Exclusivity and Hierarchy

In the debate over the term medical humanities, one objection is that the term privileges doctors over other health professionals, such as nurses, dentists, and public health professionals. The term, it is argued, is hierarchical and patriarchal and reinforces certain undesirable qualities of cultures of medicine.<sup>28</sup> For this reason, some writers suggest the term “health humanities.” This spirit of inclusivity and equality among the health professions, which we support, is reflected in journal titles such as *The Cambridge Quarterly of Healthcare Ethics* as opposed to the more restrictive and potentially hierarchical term *medical ethics*. In recent years, the British literary scholar and broadcaster Paul Crawford has championed the health humanities intellectually and organizationally.<sup>29</sup> And in 2014, Therese Jones, Delese Wear, and Lester D. Friedman (1945–) chose to title their comprehensive collection of essays *The Health Humanities Reader*.<sup>30</sup> While we support (and have ourselves published in the service of inclusivity and equality of the health professions<sup>31</sup>), we retain the term medical humanities. One reason is that the vast majority of scholarship in health humanities focuses on medicine. Another is a matter of scope; this is, in fact, a textbook in medical humanities, not health humanities. Although there is a good deal of material on public health and on nonallopathic forms of healing and care, this book is primarily about medicine. No book can be entirely comprehensive, and what we are introducing – medical humanities – might in fact someday become a sub-field of health humanities. In taking this perspective, we will keep in mind this

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critique of power and hierarchy and will incorporate such critiques into various chapters.

The Tension between the Practical/Instrumental and the Intellectual/Critical

Within medical humanities, there is also an important tension between the instrumental justification for and the intellectual practice of the humanities – that is, the tension between using the humanities to produce more humane physicians and better patient care versus practicing the humanities to generate new knowledge, insight, and critical thinking. Anne Jones (1944–), in one of the first articulations and justifications of medical humanities, warned against the assumption that studying the humanities make students more humane: “This expectation makes me very uncomfortable,” she wrote in 1987, because “[t]his expectation is a burden, not just for literature, for but for all of the humanities. We all hope that it will [make one more humane], but there have been too many examples to the contrary for me to believe in any guarantee.”<sup>32</sup> In addition, some scholars oppose the very idea of an instrumental justification for the humanities in medicine and the health professions.<sup>33</sup> In arguing against a purely instrumental approach, Jones, Wear, and Friedman write in support of “the intellectual practice of the humanities, which enables and encourages fearless questioning of representations of caregivers and patients in all their varieties, challenges abuses of power and authority, and steadfastly refuses to accept the boundaries that science sets between biology and culture.”<sup>34</sup> We believe that the tension between the practical/instrumental and the intellectual/critical forms of medical humanities is a necessary and healthy one that will continue to energize this field where the growth of knowledge fuels both cultivation and critique.

CONCEPTIONS AND GOALS OF MEDICAL HUMANITIES

In “Medicine and the Humanities – Theoretical and Methodological Issues,” Raimo Puustinen, Mikael Leiman, and Anna Maria Viljanen note several conceptions of medical humanities that we find to be helpful. They point out that in the last half century, there has been a growing recognition in clinical medicine that, as they put it, “the biological approach alone cannot address the various human phenomena that physicians encounter in their everyday practice.”<sup>35</sup> In other words (and as noted above), there has been a paradigm shift away from what might be called medical reductionism to medical holism, where patients are not reduced to diseases and bodies but rather are seen as whole persons in contexts and in relations. The chief theorists of this paradigm shift in clinical medicine cited by these authors are George Engel (1913–1999)



and his biopsychosocial model of medicine,<sup>36</sup> Eric Cassell (1928–) and his conception of personhood,<sup>37</sup> and Edmund Pellegrino and David Thomasma (1939–2002) and their philosophy of medicine.<sup>38</sup> Another important and more recent author here is the physician Christina Pulchalski, who has developed a model of spiritual care.<sup>39</sup>

Puustinen, Leiman, and Vijanen further note that along with the movement from medical reductionism toward medical holism, students and reformers in medical education in the 1960s began to question the more or less exclusive biomedical curricula of medical schools. Over the next thirty years, in “response to this criticism, courses on social sciences and humanities were included in medical curricula at many of the medical facilities in the United States.”<sup>40</sup> They continue:

It was assumed that incorporating humanities as a part of medical training could bridge the gulf between science and human experience. The aim was to educate more humane physicians and to recapture the notion of medicine as a learned profession.<sup>41</sup>

While Puustinen, Leiman, and Vijanen do not elaborate on these three goals of medical humanities – bridging the gulf between science and human experience; educating more humane physicians; and recapturing the notion of medicine as a learned profession rather than vocational training – we offer some critical reflection on these goals and specify a fourth goal that is moral and political.

### Medical Humanities as Bridge between Science and Experience

For most of the twentieth century, clinical medicine focused almost exclusively on biomedicine and discounted psychological and social information. Challenging pure biomedicine in 1980, Engel articulated a biopsychosocial model of medicine that legitimized this data and refined the ways of gathering and integrating it into patient care.<sup>42</sup> Clinical medicine, Engel insisted, is not only biomedical; it is also psychological and social. Health and illness, in other words, cannot be understood with lab results alone but only by attending to the patient’s psychological experiences and social environments. Engel’s biopsychosocial model of medicine is a medical humanities enterprise in that it attempts to bridge the gulf between science and experience. Likewise, in 1991, Cassell also attempted to legitimate non-biomedical forms of data – specifically, data related to suffering as distinguished from pain (bodies feel pain, Cassell argues, but persons suffer<sup>43</sup>). Both of these medical humanities approaches are clinically focused.<sup>44</sup> Additionally, efforts to bridge the gulf between science and experience have been greatly strengthened by the philosophical distinction between “disease” and “illness.”<sup>45</sup> Disease – what happens to the body – is understood through science. Illness – what the person experiences – is understood through eliciting patient stories,<sup>46</sup> and by asking questions such as, “What has this heart disease done to your family?” Providing opportunities for conversations about such questions

makes possible emotional and spiritual *healing*, whether or not physical *curing* (to use another important distinction) is possible.<sup>47</sup>

Other such approaches to bridging science and medicine, to name only a few, include reading stories about illness and pathographies,<sup>48</sup> watching films and theatrical representations of illness,<sup>49</sup> and viewing paintings and sculptures that represent the body in pain.<sup>50</sup> A related theoretical question to the relationship between science and experience is whether medical humanities ought to be regarded as integrating science and humanities in medical education, or, rather, whether humanities simply should be added to a largely scientific medical education.<sup>51</sup>

### Medical Humanities as Educating More Humane Physicians

One reason that medical humanities gained footing in medical schools was that, until recently, medical educators and administrators more or less assumed that teaching ethics courses would result in bolstering ethical and professional behavior. When it became clear that this assumption was not necessarily correct, a new and broader emphasis on teaching professionalism emerged. Jack Coulehan (1943–) offers several reasons why. The first is that the widespread use of expensive technology in medicine often led to a conflation of self-interest and altruism. CT scans and MRIs, for example, are powerful tools, but their unnecessary use drives up the costs of health care and reveals a conflict between patients’ needs and physicians’ self-interest. Another reason is that patients were becoming less satisfied with what technology was actually offering (e.g., when end-of-life care only prolongs suffering). Patients also began to complain that specialists seemed more interested in looking at their diagnostic machines than in listening to them. A third reason, which is related to the first, involves the rise of commercialism in medicine, an observation that patients had about the shift in the larger culture of medicine. The development of for-profit hospitals, managed care organizations, and physician relationships with pharmaceutical and biotech companies created new and visible conflicts-of-interest. In American medicine’s commercialized culture, it became clear that students needed to be taught and physicians needed to be reminded that they are professionals and that a profession is morally grounded in altruism and fiduciary responsibility.

We suggest that medical education needs to provide some guidance about what being a professional means in the new culture of medicine, that is, how to be compassionate and humane caregivers operating realistically under the modern pressures of medicine.<sup>52</sup> Medical humanities attempts to cultivate certain key virtues in and values of medicine, such as altruism, empathy, compassion, as well as certain qualities of mind by means of various reflective, interpretive, and reflexive practices.<sup>53</sup> Educating more humane physicians, we further suggest, also means that medical humanities attempts to provide guides, tools, and venues for self-care.<sup>54</sup>