Patients Are Humans Too: The Emergence of Medical Humanities

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This essay describes the origins, growth, and transformation of the medical humanities over the past six decades, drawing on the insights of ethicists, physicians, historians, patients, activists, writers, and literature scholars who participated in building the field. The essay traces how the original idea of "humanizing physicians" evolved and how crises from death and dying, to AIDS and COVID-19, expanded humanistic inquiry into health, illness, and the human condition. It examines how a wide array of scholars, professional organizations, disciplinary approaches, academic units, and intellectual agendas came to define the vibrant field. This remarkable growth offers a counterpoint to narratives of decline in the humanities. It is a story of growing relevance shaped by tragedy, of innovative programs in medical schools and on undergraduate campuses, and vital new configurations of ethics, literature, the arts, and history that breathed new life into the study of health and medicine.

Writing in 1982, philosopher Stephen Toulmin observed that the study of ethics (which traditionally meant formal, theoretical moral philosophy) had been reenergized and transformed by its engagement with medicine. In "How Medicine Saved the Life of Ethics," Toulmin explained that the ethical dilemmas of recent medicine – from death and dying, to contraception, and abortion – had catalyzed a resurgence in the once-moribund field of philosophical inquiry. Two years later, physician Eric Cassell painted a broader portrait of how problems of disease and health had nurtured humanities fields beyond bioethics. Celebrating "the place of humanities in medicine," he wrote that "the enormously increasing power of medicine to change individual lives . . . and to profoundly influence social policy had all provided rich fare for philosophical, historical, and literary examination, interpretation, and analysis."[1]

In an era when health care had become powerful but also ethically challenged, new trends in the humanistic analysis and critique of medicine flourished. For many scholars drawn to the field, medicine and the humanities were entangled in a perverse love-hate relationship in which literature, history, and philosophy promised to soften medicine's rough edges and revise its "present romance with technology."[2] In a sense, the medical humanities sought to be a counterpoint to

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technological hubris; it sought also to encourage physicians to have a deeper personal understanding of the impact of new technologies, new powers, and new health care dilemmas on people's lives. In the writings of Toulmin and Cassell, the medical humanities and ethics harbored a redemptive, utilitarian idea: that broad learning could nurture the soul of the doctor at a time when medicine, enraptured by science, was losing touch with the patient.

This essay draws on the insights of the ethicists, physicians, historians, patients, activists, artists, writers, literature scholars, and others who participated in the building of the medical humanities over the past six decades. The process began as an effort to "humanize medicine," but the agenda grew and transformed remarkably over the years. The story they tell unfolds in three stages: the period from the early 1960s to the 1980s, in which developments centered in medical schools; the years of professional expansion in the 1980s and 1990s when new journals, associations, and teaching initiatives took shape; and the particularly stunning growth of medical humanities in undergraduate colleges in the 2000s, in programs taking varied institutional forms. In what follows, I allow those who participated in this transformation to describe the diversification of work done under the heading of "medical humanities." This essay also traces how the original ideal of humanizing physicians evolved, while other goals such as exploring the human condition became more salient and as recurring crises in medicine and society catalyzed the fragmentation of the field.

The criticism articulated by Cassell and Toulmin – that medicine, in turning to science, was losing touch with patients – had been evident since the late 1950s. Increasing medical specialization was said to push doctors toward a study of disease mechanisms, and away from an understanding of illness. There was also, for example, the problem of unethical human experimentation in the post–World War II era: the revelation that leading researchers conducted experiments such as testing drugs on vulnerable patients without their consent. Such excesses spanned from the testing of polio vaccines on children in mental institutions in the 1950s to the revelation in the 1970s about the decades-long Tuskegee syphilis study, in which Black men with the disease were observed rather than treated over four decades. The disclosures suggested a need for new regulations of professional conduct. But they also suggested a need for deeper introspection about virtue and the duties of caregiving.

As Cassell explained in the early 1980s, the events of the previous two decades had catalyzed medical humanities: for "while medical science can abstract itself and deal solely with body parts, doctors who take care of patients do not have that luxury – they must work with people . . . [and are faced with] the fears, desires, concerns, expectations, hopes, fantasies, and meaning that patients bring." In this telling, the scientific guidance of physicians would always be morally impov-

erished without a fuller understanding of illness, suffering, and health, realities "better taught by literature and the other humanities."[3]

Both Toulmin and Cassell dated the birth of this humanistic critique to the early 1960s, when social movements and professional criticism produced curricular change. Over the decade, increasing numbers of women and students from minority backgrounds entered medical schools. The pressure for medical humanities programs was "initiated primarily by students," explained Cassell. Rejecting the narrowness and perceived irrelevance of scientific medical training, they "were no longer content to be taught what their faculties believe important. It was essential to the students that their classes be 'relevant' to the problems of poverty, racial bias, and political 'oppression.'"[4]

With health and health care in flux, the turmoil of the era made medical humanities necessary for addressing concerns of the moment. The deinstitutionalization of the mentally ill and their social integration provoked new questions about the meaning of illness, stigma, and the role of psychiatry in society: was it the case, as critics charged, that institutionalization was merely a scientized form of social control?[5] New legislation expanded health insurance to the elderly. But why then did the American Medical Association fight so feverishly against passage of Medicare, failing to stop it? Was this an example of the profession's commitment to economic interest and not, as they claimed, the well-being of patients? And when medical science failed in its quest to preserve life, what was the role of the physician in death and dying?[6] The subtitle of Elisabeth Kubler-Ross's *On Death and Dying* captured the era's conceptual inversions, and its shift to more patient-centered understandings: "What the dying have to teach doctors, nurses, clergy, and their own families." Worries over the failures of "the biomedical model" ranged widely, gaining even greater force in early 1970s amid burgeoning political, legal, social, and moral debates over reproductive rights, abortion, and homosexuality. Trust in medical expertise was ebbing as core institutions were buffeted by social pressures. In the early 1970s, for example, the American Psychiatric Association gathered to debate removing "homosexuality" from its standard nomenclature of mental illnesses. Little wonder that medical ethics and humanistic understandings of patients, disease, health, and society expanded in significance in this tumultuous era.

The intense demands of the era made medical practice no longer "a field for academic, theoretical, even mandarin investigation alone. . . . It had to be debated in practical, concrete, even political terms," explained Toulmin.[7] From the standpoint of the 1980s, Toulmin and Cassell saw medical humanities as a response to the "demand for intelligent discussion of the ethical problems of medical practice and research."[8] By the early 1980s, the majority of medical schools had developed programs in the medical humanities, incorporating (in one way or another) the study of literature, history, and ethics into the training of physicians to be at least

conversant with the issues swirling about the profession. Some schools had developed full-fledged departments.[9] But what neither the philosopher Toulmin nor the physician Cassell could see from the early 1980s was just how rich, diverse, and varied the field would become in the following decades.

As Toulmin and Cassell were penning their thoughts in the early 1980s, medical humanities were also taking shape in undergraduate curricula. Between 1980 and 2000, the critical humanistic analysis of medicine and health produced new scholarship in every field: in the arts, the social sciences, and in literature, history, and philosophy. New crossdisciplinary departments were devoted to the social relations of medicine and science. One such program, the one in which I earned a PhD, had been created in 1962 as the "History and Philosophy of Science," and then changed its name to "History and Sociology of Science" in 1970. The varied names suggest the multiplicity of lenses being brought to bear on the undergraduate and graduate study of science, health, and their implications for society.

In the 1980s, medical humanities shifted focus notably toward the patient's experience and the human condition. AIDS, cancer, and other health struggles provided tragic catalysts for new works in literature, art, and history. The global AIDS pandemic, for example, raised a host of new questions not only about viral origins and epidemiology, but also about condoms, sex practices, religious tolerance, gay identity, and changing sexual politics, topics demanding integrated thinking about the human condition across the sciences, public health, social sciences, and humanities.

Where might one seek insight into this new health crisis? Was it perhaps Larry Kramer's 1985 autobiographical play, *The Normal Heart*, about enduring the early years of AIDS prejudice, indifference, struggle, and fear in New York City? Or perhaps the reflections of physician Abraham Verghese in *My Own Country: A Doctor's Story of a Town and Its People in the Age of AIDS*?[10] Reviewing Verghese's book in *Literature and Medicine*, Joseph Cady explained that AIDS literature had become vast and had been produced mostly by people vulnerable to the disease. Verghese's contribution was different, telling his story as a foreign medical graduate in small town Tennessee chronicling the social trauma: the "HIV-positive heterosexual woman…infected by her bisexual husband, hemophiliacs with AIDS…and people with transfusion AIDS (Will and Bess Johnson, who posed an extra level of challenge as well-to-do, 'pillar of the community,' fundamentalist Christians who insist on keeping their infection secret)."[11] The nation's AIDS experience made clear that to fully understand the unfolding health tragedy demanded creative storytelling, narrative insight, introspection, and deep sensitivity to the complexity of the human condition. Kramer and Verghese were only two among many medical humanities ideals.

In medical education, new texts were pushing the field forward; new lines of inquiry and pedagogy were opening. When I taught in the medical school at the University of North Carolina at Chapel Hill in the 1990s (in the department of social medicine), humanizing the physician remained the central driving conceit. The redemptive ideal generated a new textbook in 1997, the *Social Medicine Reader*, a collection of fiction, essays, poetry, case studies, medical reports, and personal narratives by patients and doctors compiled for teaching. The *Reader* aimed to "contribute to an understanding of how medicine and medical practice is profoundly influenced by social, cultural, political, and economic forces." Elsewhere, physician Rita Charon and literary scholar/ethicist Martha Montello were also compiling essays for an edited collection for a new enterprise labeled "narrative medicine." As they observed, storytelling underpinned all thoughtful caregiving: "How the patient tells of illness, how the doctor or ethicist represents it in words, who listens as the intern presents at rounds, what the audience is being moved to feel or think – all these narrative dimensions of health care are of profound and defining importance in ethics and patient care."[12] Such developments transformed medical education in the 1990s. "By 2004," wrote medical historian Emily Abel and sociologist Saskia Subramanian, "88 of the 125 medical schools surveyed by the American Association of Medical Colleges offered classes in the human dimensions of care, including treating patients as whole people, respecting their cultural values, and responding empathetically to their pain and suffering." However, these courses were only "a tiny fraction of medical-school curricula."[13]

Driven by such initiatives, the 1980s and 1990s would be an era of acquisitions, new ventures, and mergers in the medical humanities: new journals established, professional associations combined, and novel academic collaborations explored. In 1980, for example, the *Journal of Medical Humanities* was founded, followed two years later by *Literature and Medicine*. In 1998, three organizations – each representing different facets of the emerging field – merged to produce the American Society of Bioethics and the Humanities (ASBH). The oldest of the three, dating to 1969, was the Society for Health and Human Values (SHHV). The Society for Bioethics Consultation had been founded in the mid-1980s, while the American Association for Bioethics had been established only four years before, in 1994. As the ASBH's founding president, bioethicist Loretta Kopelman, reflected, the term "humanities" was a reassuring rubric particularly for the non-ethicists, a group that encompasses a vast array of disciplines and specialties:

> SHHV had members from many fields including health professionals, law, religious studies, literature, pastoral care, social science, history, visual arts and student groups. Some worried that this diversity of approaches would not be valued in the same way in a new organization. For many of those fearing such marginalization, "humanities" came to stand for inclusiveness and "bioethics" for the sort of rigor in addressing

> problems such as are found in publications in philosophy, law, social science or academic medicine. The title "American Society of Bioethics and Humanities" reflected that we wanted all groups to thrive in ASBH.[14]

Many of these new ventures proved to be durable, creating the institutional supports, professional associations, journals, texts, and teaching practices necessary to sustain the field. Others, such as the Society for the Arts in Healthcare founded in 1991, were short-lived and difficult to sustain.

By 2000, divergences in the medical humanities agenda appeared, inevitably so. In medical schools, the humanities presence remained small and there would be unavoidable tensions as humanists worked within the overwhelming science-based curriculum. Reflecting on the challenge of balancing history, theory, and practice in medical education, bioethicist Thomas McElhinney observed that

> the changes in medicine caused by scientific discovery and technological developments, on the one hand, and social and political transformations, on the other, increasingly highlighted the impossibility of a complete medical education structured only on theory and practice (i.e., basic science and clinical training).[15]

Faced with the demands of science and clinical education, students' responses to the little humanities they encountered varied, said McElhinney: "the humanities will be a distraction to some but an oasis in an otherwise arid environment for others."[16] The serious and profound need for humanistic insight remained obvious even if curriculum space was limited. By contrast, however, undergraduate college education in the 2000s provided fertile soil for program building and expansive institutional development.

Since 2000, "health humanities" in undergraduate education has expanded as a vibrant complement to the "medical humanities" in medical schools, a development that moved the field significantly beyond its narrow ideals of humanizing physicians. Between 2000 and 2010, the number of undergraduate baccalaureate programs in the health humanities jumped from eight to over forty, followed by another stunning increase in the next decade. By 2021, the number of such programs had reached 119, an eightfold increase since 2000 as one recent survey by humanities and bioethics scholars Erin Gentry Lamb, Sarah Berry, and Therese Jones observed. At the same time that a crisis in the humanities brewed, the once niche field was flourishing. As Lamb, Berry, and Jones noted, "at a time when Liberal Arts education, and humanities programs in particular, are under fire in many public quarters," health humanities programs were serving a growing, keenly interested population of students (many of whom hoped to enter health care careers).

The utilitarian impulse to produce better caregivers persisted, but the locus of humanistic health education was shifting to undergraduate curricula. And in this

context, the critical sensibilities of the medical humanities sharpened. Colleges across the nation discovered that these years were "an ideal time for students to develop skills valuable . . . to providing humanistic health care across a wide range of health care fields." Reaching younger students prior to entering health careers cultivated "habits of mind that prepare students for critical and creative thinking, identification of internal biases, and ethical reasoning in decision-making processes – all of which are critical skills for participating in the complex system of U.S. healthcare."[17] The model gained traction, drawing together students from across disciplines and a range of health-oriented humanities scholars in new teaching and research initiatives.

Commenting on the diverse expansion of such programs in 2009, historian Edward Ayers observed that "we need to understand the many contexts in which the humanities live. They live in departments and disciplines, of course; but they also live in new places, in new forms, and in new combinations."[18] Medical humanities was one such novel combination. Drawing on cultural studies, women's studies, disability studies, and other burgeoning fields, programs of medical humanities defined a "rapidly growing field, celebrating the ability of the humanities, as one program put it, to provide 'insight into the human condition, suffering, personhood, our responsibility to each other.'"[19] Medical humanities became, for many commenters like Ayers, a leading example of the thriving humanities, a vibrant counterpoint to widespread narratives of decline.

That same year in an astute editorial in *Medical Humanities*, physician Audrey Shafer acknowledged the diverse field was showing new academic fracture lines. Not only did institutional and pedagogical goals differ, but gaps had opened between medical humanists who worked directly with patients or in health care settings and those who worked in other educational contexts. Collaborations suffered because "for instance, a performing arts department will have different theoretical underpinnings, methodologies, scholarly activities and products from a philosophy department."[20] Medical humanities was an intellectual hodge-podge, in Shafer's view, suffering from an identity crisis. Yet despite tensions among scholars with different qualifications, degrees, and agendas, the enterprise remained vibrant with new "demarcations, dilemmas, and delights." For Shafer, the struggle to hold the field together was itself productive, for "when medical humanities ceases to struggle with what it encompasses . . . then it will cease to be medical humanities."[21]

Many program builders in undergraduate settings did not share Shafer's worry about the field's "identity and boundary bumping," however. "Health humanities" and "medical humanities" proved to be popular, versatile, and decidedly flexible rubrics for program building in undergraduate contexts. Programs emerged under a growing array of headings: "History, Health, and Humanities," "Health and Society," and "Medicine, Science, and the Humanities."[22] If some

embraced narrative ethics and centered the study of literature while others foregrounded history or ethics, this diversity reflected the robust range of what medical humanities had become. The goal remained broad, cross-disciplinary education about the human condition, and deep introspection connecting scholars across fields who were drawn together in teaching and researching the challenges of health and healing.

The agenda of medical humanities had built over time, with no single discipline claiming exclusive ownership over the enterprise. Assessing the field, literature scholar Sari Altschuler pointed forward in the conclusion to her 2018 book, *The Medical Imagination*. In her view, the humanities agenda in medical schools had made modest gains, confining itself to a limited agenda by "mostly aiming at improving physician empathy rather than at shaping and expanding medicine's ways of knowing."[23] Meanwhile, programs run by humanists in undergraduate settings remained too heavily focused on the utilitarian task of preparing aspiring health care workers. Both approaches sought "to bring a sense of the human back to medicine that risked being too governed by dispassionate science, routinized procedure, and market logic."[24] These foundational functions of the humanities in medicine (its redemptive capacity for humanizing caregivers and seeing the humanity of patients) had not changed. If anything, they had expanded remarkably in reach and scope, finding new audiences, and developing in new venues.

With this expansion, scholars in a field that had begun modestly (in hopes of humanizing physicians and exploring *the human condition*) now confidently asserted that the very habits of analysis in humanistic inquiry exemplified, in themselves, important "ways of knowing" about health. To Altschuler, "the number and breadth of medical and health humanities programs offer a terrific opportunity" to move beyond empathy building in medicine, and to embrace a bolder vision: "the recognition that humanists have an important and distinct set of tools for knowing the world, as do health professionals."[25] Building on the energetic developments of the past decades, she called on humanists to engage with medical science from a new standpoint – to find common ground with medical educators by embracing the language of "competencies": practical skill development as the bedrock of medical training. By now, these skills could be clearly articulated as "humanistic competencies – which include narrative, attention, observation, historical perspective, ethics, judgement, performance, and creativity."[26] The list offered a lovely shorthand for the approaches, methods, and practices encompassed within the health humanities. These competencies also highlighted the fraught challenge ahead; the building of medical humanities would involve ceaseless struggle over boundaries and demarcations, even as its core commitment remained restoring humanistic understanding to the vast biomedical and health enterprise.

In the end, the remarkable growth of the health humanities over the past six decades is a story of tragic relevance, driven by the awareness not that medicine had "saved the life of ethics" as Toulmin had noted, but rather by recognition that new configurations of ethics, literature, the arts, and history were vital for breathing life into medicine.

As the medical humanities have widened their reach, one theme has persisted from the early years: professional and human crisis has spawned the search for meaning and introspection about life, illness, recovery, human suffering, the care of the body and spirit, and death. Medicine's social dilemmas, its professional controversies, human health crises, social tensions over topics from AIDS to abortion and genetics, as well as the profession's very identity and its claim to authority have catalyzed and fed a growing demand for answers about meaning. The recurring crisis has generated a style of humanistic insight that has flourished not only within traditional disciplines but also in the interstices.

The flourishing of medical humanities is a story of shifting energies: the emergence of new lines of inquiry, new institutional homes, and novel journals and professional associations. As the field has grown, its questions about illness, disease, and the pursuit of health have become more prominent across the academy and beyond its boundaries. The work has adapted to new trends in health movements, disability studies and activism, and questions of race and gender in relation to health. Even as new programs have developed, the work of health humanities has become ever more salient in the disciplines of history, literature, the arts, and in philosophy and ethics.

This expanding humanist venture – spanning from undergraduate and graduate teaching and research to broad public engagements – refutes the narrative of a "humanities in decline." Redemption and humanization of the practitioner remain goals, as does the deep appreciation of suffering, recovery, and the illness experience. But the past decades have seen a wider critique: an insistence that the tools of the medical humanities are not merely restorative gap-fillers for what is lacking in scientific and technological insight, but that their discernment about the self and identity, suffering and illness are the primary lenses for understanding essential features of human experience, health, and society. The medical humanities provide, then, the means by which we understand the complex problem of how humans respond to illness, and how humans assess the role of science and medicine in the enterprise of healing.

In the same way that the human tragedy of AIDS confirmed the relevance of medical humanities in the 1980s and 1990s, today's global coronavirus pandemic (and its underlying issues of disparate suffering, loss, blame, conflicted belief, social inequality, misinformation, and varied cultural responses) catalyzes yet another wave of interest in health humanities. And few of COVID's challenging questions revolve around doctoring or patients alone; in COVID, the health and

well-being of a contentious and fractured *public* raised vexing questions well suited for medical humanists.

As we weather recurring waves of COVID, it has become commonplace for media to turn to medical humanities scholars for insight and guidance. What could literature or history teach us about the social responses to the current pandemic? asked National Public Radio. Could the history of past pandemics provide insight into the current crisis, or serve as guides for the building of effective social responses and healthier, more equitable societies? To answer such questions, public media has sought answers from scholars like French professor Alice Kaplan, who was busily writing a new introduction to Camus's *The Plague*. In early 2020 during the first wave of COVID, sales of the book skyrocketed in Europe. "People are saying in the French press, what do you absolutely need to read in this time? You need to read *The Plague*," Kaplan explained. "Almost as though this novel were a vaccine – not just a novel that can help us think about what we are experiencing, but something that can help heal us."[27]

The medical humanities began in crises and critiques of medicine, and crisis continued to make the health humanities vital, timely, and necessary. To be sure, the utilitarian ideals remained focused on creating well-rounded medical practitioners. But the field now encompasses a grander and more widely institutionalized, and still richly debated, promise of healing and restoration through literature, the arts, history, and ethics.[28] So while it is true that medicine "saved the life of ethics," it is also the case that over these decades, the medical humanities has breathed new life into the humanities while also offering society a kind of healing that medicine itself cannot provide. This remarkable growth offers a counterpoint to narratives of decline in the humanities. It is a story of growing relevance shaped by tragedy, of innovative programs in medical schools and on undergraduate campuses, and vital new configurations of ethics, literature, the arts, and history that have profoundly rejuvenated the study of health and medicine.

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