The Disciplinary Challenges of Narrative Medicine

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In the opening of "A Burst of Light: Living with Cancer," Audre Lorde writes about her visit to an oncologist after a large mass is discovered in the right lobe of her liver. The highly regarded specialist considers it very likely that the tumor is malignant and suggests immediate surgery. Lorde, who has undergone a mastectomy and treatment for breast cancer in the past, responds that she needs time to "feel this thing out and see what's going on inside" herself first. She does not want to act out of panic, she explains. The oncologist, however, will brook no delay. As Lorde describes:

> What the doctor could have said to me that I would have heard was, "You have a serious condition going on in your body and whatever you do about it you must not ignore it or delay deciding how you are going to deal with it because it will not go away no matter what you think it is." Acknowledging my responsibility for my own body. Instead, what he said to me was, "If you do not do exactly what I tell you to do right now without questions you are going to die a horrible death." In exactly those words.
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> I felt the battle lines being drawn up within my own body.

In vivid detail, Lorde describes the pernicious confluence of medical paternalism and bias in this painful scene:

> From the moment I was ushered into the doctor's office and he saw my x-rays, he proceeded to infantilize me with an obviously well- practiced technique. When I told him I was having second thoughts about a liver biopsy, he glanced at my chart. Racism and Sexism joined hands across his table as he saw I taught at a university. "Well, you look like an intelligent girl", he said, staring at my one breast all the time

> he was speaking. “Not to have this biopsy immediately is like sticking your head in the sand.” Then he went on to say that he would not be responsible when I wound up one day screaming in agony in the corner of his office!

The alienation in this tale is acute. As clinician-philosopher Edmund Pellegrino explains, “To care, comfort, be present, help with coping, and to alleviate pain and suffering are healing acts as well as cure. In this sense, healing can occur when the patient is dying even when cure is impossible ... Cure may be futile but care is never futile.” The absence of such comfort and presence in the scene Lorde describes is itself a material form of injury.

One need not have faced a diagnosis of cancer to feel some recognition—though not to say full understanding —of Lorde’s story. One experiences this type of objectification all too frequently upon entering a doctor’s office or hospital. One hears the odd rhythms of an unfamiliar language reducing patients to injury or pathology, mapped to a disease entity, and becoming “the knee in room 3”—an assemblage of seemingly fungible organs and body parts, each treated by a different service of the hospital. One becomes, too, a virtual body of electronic medical records and digital scans, with the scope of human experience relegated to “social history” in the medical chart. There are, to be sure, many works of autobiography and fiction that reflect tremendous compassion and effectiveness in the clinical setting, just as our experiences of healthcare are complex and varied. However, the discontent reflected in these passages is indeed pervasive.

Clinicians increasingly feel diminished and disempowered as well, caught in the maw of bureaucratic documentation and burdensome regulation, estranged from the call to care and the intimacy of the doctor–patient relationship. Memoirs by physicians—often focusing on the years of medical school and residency— invariably recount experiences of profound bewilderment, humiliation, fatigue, brutality, and a loss of empathy and idealism.

How did we get here? [For this brief history, I am in part indebted to my colleague Danielle Spencer's article on NMED in the Routledge Companion to Philosophy of Medicine.]

In the United States, Abraham Flexner's (1910) highly influential Carnegie Foundation report. Emphasis on biomedical science in medical education. Recommendations for admissions requirements and curricular focus have remained largely intact in medical education. Inspired by the German system of that era and concerned primarily with standardization and scientific rigor. But Flexner also acknowledged that medicine requires "requisite insight and sympathy on a varied and enlarging cultural experience" as well as ethical and social responsibility. He has been criticized, however, for not emphasizing humanistic values. In 1926 Flexner critic Francis Peabody reminded medical students that "one of the essential qualities of the clinician is interest in humanity, **for the secret of the care of the patient is in caring for the patient.**"

Throughout the 20th century other critics of Flexner weighed in. Among them, to mention just one example, was Eric Cassell. Criticizing the legacy of Cartesian mind-body dualism, Eric Cassell wrote in 1982 that, "Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity."

During the late 20th Century, studies, including one by my CU colleague psychoanalyst Eric Marcus, demonstrated a dramatic drop in students' levels of empathy and compassion throughout medical school. Witings by patients and clinicians reflected growing cynicism and estrangement.

Such a rising tide of discontent in health care, writes Spencer, "joined with social trends and political movements of the 1960s and 70s—the civil rights movement, the growth of women's health awareness, community health centers, patient advocacy, and disability rights, among many others—combining to produce a range of innovative and interdisciplinary responses." Among those response was the biopsychosocial model, as well as patient-centered care, relationship-centered

care, and the patient's rights movement. Medical humanities and "Literature and Medicine" were introduced into the curricula of medical schools in the U.S. beginning in the early 1970s.

Many of these trends coincided with a "narrative turn" in the humanities, social sciences, and popular culture beginning in the later decades of the 20th century. Fields as diverse as history, sociology, cognitive science, law, business, psychology, literature, and cinema experienced a resurgent recognition of the prevalence and relevance of narrative—a revival of interest in storytelling taking different forms in various disciplines.

Narrative medicine rose in this context, responding to the crisis in health care and drawing upon scholarship in the humanities and social sciences. There is no single starting point to the field, but physician-scholars Trisha Greenhalgh and Brian Hurwitz's (1998) formative Narrative Based Medicine: Dialogue and Discourse in Clinical Practice notably united clinicians, historians, psychotherapists, literary scholars, computer scientists, creative writers, biologists, epidemiologists, anthropologists, ethicists, and educators bridging biomedicine and the humanities.

In 2003, a group of scholars, clinicians, and writers joined with Rita Charon in 2003 to think systematically about why literary and narrative work in clinical settings might help clinicians and their patients. With funding from the National Endowment for the Humanities, we met regularly over 2 years to take up these questions. The group included internist and Henry James scholar Rita Charon; Victorianist and cinema scholar Maura Spiegel; philosopher Craig Irvine; novelist David ; psychoanalyst Eric Marcus; patient advocate Pat Stanley, and pediatrician and social theorist Sayantani DasGupta. All of us were engaged in some way with writing about and teaching humanities and medicine.

We taught one another theoretical frameworks from our disciplines that shed light on our questions—D.W.Winnicott on play and reality, Adam Smith on moral sentiment, bell hooks and

Paulo Freire on liberatory teaching, Maurice Merleau-Ponty on the body, Henry James on the novel and much more. Intersubjectivity, social justice, embodiment, relationality, reflexivity, creativity, and doubt were the signal concepts we worked with, while close reading and creative writing became signature methods of our work. We conceptualized and undertook research projects to learn about the consequences of this work in various settings. With the inspiration of a number of consultants doing stellar work in medical humanities elsewhere, we emerged with a conceptual framework that focused on the development of attention, the necessity of writing or other forms of representation, and the ultimate goals of affiliation with patients, colleagues, society, and the self. By designing and teaching graduate courses and intensive introductory workshops for clinicians, we honed our original theoretical notions into a systematic and coherent set of principles and practices. In 2006, Dr. Charon published her groundbreaking 2006 book, *Narrative Medicine: Honoring the Stories of Care*, in which she provides a comprehensive and systematic introduction to the conceptual principles underlying narrative medicine, as well as a practical guide for implementing narrative methods in health care.

Since then, this work has evolved outward, inward, and depthward. The faculty of the masters program in narrative medicine have published numerous articles and books that have defined and advanced the field. In 2016, seven of our core faculty (Charon, DasGupta, Hermann, Irvine, Rivera-Colon, Spencer, and Spiegel) published *The Principles and Practice of Narrative Medicine*, which provides the authoritative starting place for any clinicians or scholars committed to learning about and eventually teaching or practicing Narrative Medicine. This book received the prestigious Perkins Prize in 2017. Our confluence of primary care medicine, narratology, literary theory, and phenomenology has evolved into a fluid, international, many-sourced convergence of thought and practice. From quarters as diverse as Zen Buddhist contemplative practice, relational psychoanalytic theory, and postcolonial theory, we and our colleagues have articulated rich,

provocative, bottomless challenges to the current injustices and failures of health care. In addition to the Master of Science in Narrative Medicine and the low-residency certification program for distance learning at SPS, our narrative medicine project at Columbia, initially funded by the National Endowment for the Humanities and subsequently by the National Institutes of Health and the Josiah Macy, Jr. Foundation, has matured into required curricula in narrative medicine in all four years of Columbia's medical school, interprofessional education for students and faculty from eight of Columbia's schools and programs in the health professions, thousands of persons trained in the basics of narrative medicine at intensive workshops at the medical school, national and international partners working with us worldwide to develop narrative medicine programs elsewhere, and productive collaborative contact with groups far outside health care who find in the principles and practice of narrative medicine something of value.

By no means a unitary field by now, narrative medicine has come to stand for a set of convictions and methods that fortify clinical practice with narrative skills to listen, to recognize, to witness, and to be moved to action on behalf of patients through close attention to their situations. We hope that our underlying commitments to attention, representation, and affiliation continue to guide others who join us in this effort to improve patient care through strengthening clinicians' narrative capacities.

Why stories?

> "Story is the mind's way of molding a seeming whole from out of the messiness of the distributed, modular brain. At the same time, shared stories are the only way anyone has for escaping the straightjacket of self. Good medicine has always depended on listening to histories. So any attempt to comprehend the injured mind naturally inclines toward all the

devices of classic storytelling. . . . Only inhabiting another's story can deliver us from certainty." Richard Powers

Stories are the primordial means through which we make sense of and convey the meaning of our lives. It is to this that the philosopher Paul Ricoeur points when he speaks of "life *as an activity and a passion in search of a narrative*." Indeed, for Ricoeur, our life is "the field of a constructive activity, by which we attempt to discover . . . the narrative identity which constitutes us."

Ricoeur reminds us that we always already live in imaginative worlds. Consciousness itself is shaped by narratives we have heard. Hence, what we call experience is not a pure blank reality. Stories in which we grew up, that told us what was possible, instilled in us a sense of right and wrong. Familial stories, national stories, religious stories.

Narrative hermeneuticists Jens Brockmeier and Hana Meretoja reinforce this point: "[E]xperience itself involves constant interpretation and . . . our narrative self-interpretations and the cultural frameworks in which we are entangled affect how we experience things in the first place. If cultural narratives already mediate experience as it is lived and we keep reinterpreting our experiences, as new experiences and points of view alter and challenge our former interpretations, and new stories we encounter prompt us to refigure our narrative identities, there is no need to view narrative as a matter of imposing order from without. [F]rom the very beginning, narrative is woven into the fabric of life in a variety of ways. It is not found, nor is it imposed, nor is it the result of a representation; rather it is created through practices of meaning construction. These narrative practices also take part in constituting our sense of who we are as individuals and as communities . . . ."

A story is something whose content cannot be reduced to analyzable data. Meanings are not extractable from a story as if they exist separate from its form. Instead, a story relinquishes its meaning only to the reader or listener who undergoes all the story's elements—its plot, its genre, its diction, its metaphors, its allusions, and, most critically for Ricoeur, its temporal configuration, which makes time itself *human*. The reader or listener who enters that story experiences the integrated flow of all these features, none of which is elective to the full measure of the story. The full story is required for the reader to understand its ethical or personal or affective meaning.

Narrative medicine is medicine practiced with narrative competence, which we define as the fundamental human skill of recognizing, absorbing, interpreting, and being moved to action by the stories of others.

One way to develop the narrative competence required of narrative medicine is through the study of literature and the development of the skills of close reading. To listen to patients' stories with a view toward understanding how the storytellers find themselves in their present situation requires the same narrative competence used in reading a literary text. We propose that the close reading of great literature develops the narrative competence necessary to understand the complexity and ambiguity of human life.

Ricoeur and other narrative hermeneuticists have helped us to understand the crucial role literature plays in this interpretive, world-shaping process of meaning creation.

Jens Brockmeier and Hana Meretoja reinforce this point:

> "[L]iterary narratives . . . have real, world-creating effects. . . . Involving the full realm of the imaginary and experimentation with unconventional narrative forms, [literature] can question our taken-for-granted storytelling practices and open new possibilities of being, acting, experiencing, and thinking. Narrative hermeneutics conceives of literature and the other arts as forms of cultural self-understanding that have existential relevance, exploring

most fundamental issues of our existence. It examines what makes artistic forms of narrative so uniquely appropriate to expand and, indeed, transcend the horizon of our understanding and imagination."

In writing about the fiction of Toni Morrison, philosopher George Yancy reinforces this point about the power of literature to expand and transcend the limited horizons of our own understanding and imagination:

> "Morrison is able to place the reader into an imaginative lived space, a powerful narrative space that is able to articulate modalities of lived existence . . . Hence, one might say that Morrison posits philosophical questions that are linked inextricably to narrative. After all, our lives are lived narratives, journeys of pain, endurance, contradiction, death, intersubjectivity, suffering, racism, sexism, terror, trauma, joy and transcendence. Avoiding abstract . . . discourse, Morrison reveals the power of literature to embody the flesh and blood reality of what it means to-be-in-the-world."

The literary text opens before it a world of possible experience, in which it is possible to live. Not something closed in on itself, the text is a projection of a new universe distinct from that in which we live. When we read, therefore, we belong, at the same time, to the world-horizon of the work in imagination and the world-horizon in which the action of our "real" lives unfolds. Ricoeur emphasizes that stepping into the horizon of a literary work allows us to "try on" its possibilities.

Each new narrative work opens new horizons in which we might experience, explore, and try on alternative realities, alternative ways of being-in-the-world.

We teach narrative medicine by teaching close reading, creative writing, responding to the writing of others, co-constructing narratives. Clinician and literary theorist Rita Charon writes, that,

> "Not only the reading of the text but talking about it and writing in its shadow seem to be required for the reader to achieve dividends of the learning. In the formation of the clinician, these powers of sight and meaning, achievable by the close reader and writer, are the necessary equipment for coming to envision and comprehend the meaning-making of patients, families, clinicians, and wider communities. Once they have learned to be close readers, they have the capacity to become close listeners. Once they have strengthened their skills of representation in writing, they can lend this skill to the patients for whom they care and whose accounts they may attempt to configure into a written narrative."

I'd like to bring this to life for you by describing an actual experience of putting literature to work in this way, in service of opening horizons into which one might project new possibilities, through which one might reflect on the meaning of one's own experience and open the doors to empathic relationships with others.

This suppression of self-care was brought home to me in a particularly poignant way by a story written by a 4th-year medical student, Ashley, for my ethics course. Ashley's story was about an experience she'd had almost two years earlier, as a third-year medical student, on the first morning of her first inpatient rotation. Early that morning, a patient named Mary was admitted to Ashley's hospital floor. Mary, who was not much older than Ashley, had been hospitalized with sepsis, caused by immune suppression from chemotherapy. Shortly after arriving on the floor, Mary developed Acute Respiratory Distress Syndrome. The entire team ran to her room, and the Chief Resident told Ashley to sit by the bed and encourage Mary to relax. For more than five hours, while residents and attendings ran in and out of the room doing everything in their power to arrest Mary's respiratory decline, Ashley held Mary's hand, repeating, over and over again, "Just breath. Relax, it's going to be okay. Breath. Please try to relax. We're all here for you. Just breath." When Mary stopped breathing, the Chief Resident pushed Ashley away from the bed, and he and

the rest of the team began the code. Death was declared several minutes later. The team abruptly left the room, leaving Ashley alone with Mary's battered body. No one ever spoke to her about Mary's death.

When Ashley finished reading this story to me, she looked up and said, through her tears and without irony, "I just wish I'd been able to do something for Mary, like everyone else. I felt so helpless. Just useless and in the way." In the two years since Mary's death, Ashley had never shared this story with anyone at her school.

Writing, reading, and discussing the story of one's alienation, therefore, are often the first steps in overcoming it. This was certainly true for Ashley. During our discussion, we considered the role the "character" of the medical student plays in the story of Mary's death. In this story, Ashley discovered, the student plays a much more important role than any of the doctors: Mary would have died whether or not Ashley was there, but her death would have been far less peaceful. While the importance of Ashley's role seemed immediately obvious to me, as it would to most readers of her story, Ashley had not, previously, been encouraged to acknowledge the moral authority of her actions. On the contrary, her professional training had actively discouraged this acknowledgement. Every death, for medicine, is simply a defeat—end of story—at the hands of its worst enemy. Writing and sharing her story offered Ashley a means of memorializing Mary's death—a means of preserving the memory, and so placing the meaning, of an event radically dislocated by her professional training. This was healing for Ashley. Reflecting on the story of her life, of Mary's life, of their lives, Ashley heeded the imperative to care for herself.

Obviously, writing and relating the story of Mary's death could not possibly repair all of the psychic, and ethical, injuries Ashley suffered during her medical training. It was, however, an essential first step in what must be a continuous, ever-evolving narrative process: for Ashley, as for all health professionals, healing requires an ongoing commitment to narrative self-reflection. This

commitment goes beyond the reparation of injuries wrought by the modernist heroics of the medical academy. Indeed, narrative ethics requires and promotes a fundamental change in the very culture of the medical academy itself.

It wasn't enough for Ashley to have this experience with her patient. She had to write about the experience, had to narrate it, and share this story with others. This sharing piece is crucially important, and marks how this process is different from keeping a diary or journal.

Writing and sharing her story offered Helen a means of memorializing Caldwell's death—a means of preserving the memory, and so placing the meaning, of an event radically dislocated by her professional training. This gives her resources with which to remain more attentive the next time she is faced with a patient like Caldwell. Attention and Representation are inter-related. This was healing for Helen—a healing that is crucial if Helen is going to be able to treat her patients without building a wall through which empathy might never penetrate.