

THE ROUTLEDGE COMPANION TO PHILOSOPHY OF MEDICINE

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NARRATIVE MEDICINE

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Listening is a rare happening among human beings . . . [it] is a primitive act of love, in which a person gives self to another's word, making self accessible and vulnerable to that word.

— William Stringfellow, *A Keeper of the Word* (1994: 169)

Introduction

As physician and literary scholar Rita Charon describes, narrative medicine is medicine practiced with the “narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness” (Charon 2006: 4). One of its fundamental tenets is the importance of *narrative competence*, of attending to the form and structure of storytelling. A clinician taking a patient history, like the skilled reader of a literary work, must recognize and understand not simply data as it fits into checkboxes of the electronic medical record but also the *way* the patient relates his experience, including context, narrative voice, tone, figurative language, and temporality. Where does the account begin? What is left out? Which perspectives are represented, and how? Further, how do both teller and receiver construct meaning reciprocally—and what is the form and ethics of this exchange?

Such focus on clinical care enriched and strengthened by an understanding of narrative is integral to the field, which also includes varied areas of enquiry and modes of practice. Inherently interdisciplinary, narrative medicine draws upon literary theory and criticism, philosophy, creative writing, disability studies, psychoanalytic theory, critical race theory, qualitative research, sociology, and oral history, among other discourses. Key themes include:

- Humanistic healthcare education and training, with a particular emphasis on close reading
- Progressive pedagogy and a commitment to social justice
- Scholarship and creative expression about experiences of illness, disability, and caregiving

Through such practices the field explores the operation of storytelling in the clinical encounter, in conceptions of the self and intersubjectivity, in broader narratives informing health policy and social justice, and in the relationships among these different contexts.

Genealogy

Narrative medicine affirms and explores the intrinsically narrative and humanistic nature of medical practice, offering a corrective to an accelerating trend toward bureaucratization and specialization, which has proven increasingly alienating for clinicians and patients alike.

Given the field's emphasis on narrative, it is especially important to note some of the circumstances in health care, society, and academic discourse contributing to its genesis and evolution—and also to acknowledge the contingency and selectivity of any particular account.

In the United States, Abraham Flexner's (1910) highly influential Carnegie Foundation report instantiated a robust emphasis on biomedical science in medical education, and until recent years his 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, Flexner also acknowledged that medicine requires "requisite insight and sympathy on a varied and enlarging cultural experience" as well as ethical and social responsibility; however, critics point toward the omission of such humanistic values in his model, which describes the human body as "belonging to the animal world." Lamenting what he viewed as the growing impoverishment of the doctor-patient relationship, in 1926 Flexner critic Francis Peabody memorably 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 many voices joined Peabody in addressing the scope of care and warning against dehumanization in medical practice. Eric Cassell, decrying the alienating legacy of Cartesian mind-body dualism, explained 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" (1982: 639). Similarly, Charles Odegaard (1986: 16), critiquing Flexner's mechanistic description of the human body, cautioned that

The physician who is educated to see his patient as only a collection of interrelated tissues and organs is not seeing his patient whole; and, except as he may be aided fortuitously by untutored intuition, he will not be able to deal with his patient's health in all its aspects.

Over time such calls to tutor the clinician's intuition became increasingly acute as awareness grew of the alienating effects of health care education and practice; studies demonstrated a dramatic drop in students' levels of empathy and compassion throughout medical school, and writings by patients and clinicians reflected growing cynicism and estrangement.

Such a rising tide of discontent in health care 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. The biopsychosocial model promulgated by George Engel (see Chapter 40) emphasizes the multifaceted psychological and social context of health and illness, while patient-centered care, relationship-centered care, and the patient's rights movement privilege patient/family values as well as collaboration and transparency in medical decision-making. The hospice movement, influenced by the work of Elizabeth Kübler-Ross and Cicely Saunders, offers a more humanistic approach to the processes of dying and grieving. The field of bioethics arose in the wake of the Nuremberg Trials concerning human experimentation by Nazi researchers and clinicians as well as the abuses of research projects such as the Tuskegee syphilis study and the Willowbrook hepatitis experiments, with Henry K. Beecher (1966) acting as a particular catalyst, pointing toward "ethical errors" and "troubling practices" in human experimentation. Bringing philosophy into conversation with health care, law, and sociology, bioethics addresses questions in research ethics, medical decision-making, and social justice, with particular emphasis on issues raised by new developments in biotechnology. In addition, medical humanities as well as "Literature and Medicine" entered the curricula of medical schools in the U.S. beginning in

the early 1970s, accentuating the study of literature—typically topical works oriented toward clinical care and illness—as a means of improving clinicians’ understanding and enriching ethics education. This era also saw a tremendous growth in writing and activism about experiences of illness, disability, and caregiving, which accelerated dramatically during the AIDS epidemic of the 1980s and ‘90s.

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. Each of these discourses possesses its own framework and terminology, and so a brief précis can, at best, gesture toward these contexts: in literary criticism and theory, the narrative turn is comparable in magnitude to the earlier “linguistic turn,” indicating a move away from deconstructionism while retaining a keen attentiveness to the particularity and contingency of narratives and their role in structuring knowledge and power. Meanwhile, Hayden White elaborates an influential formal analysis of historiography—its modes of emplotment, argument, and ideology—exploring the narrative tropes structuring our understanding of the past. Similarly, in areas such as post-colonial and feminist studies the identification of hegemonic narratives offers insight into their ideological effect on historical and scientific orthodoxy, as in Homi Bhabha’s study of narrative and nation-states, or Donna Haraway’s exploration of “allowable stories” in biology.

In philosophy Richard Rorty offers an influential narrativist methodology, turning from scientific definition and argument toward a literary style, analyzing philosophical works in comparison with novelistic fiction and stressing the importance of “telling a new story.” Literature and the arts, too, reflect a resurgent concern with storytelling after the interest in “anti-narrative” exemplified by the French *nouveau roman*, and (in some quarters) moving beyond what Paul Ricoeur described as a “hermeneutics of suspicion”—a deep-rooted distrust of narrative’s seemingly illusive legerdemain and power to ideologically conscript the reader. The field of narratology—the study of narrative—itself shifts from a structuralist conception of narrative coherence grounded in literary forms towards “postclassical” narrative theory, embracing a broader range of modes of expression and media types: human exchange, performance, dance, visual art, spoken word, interactive online communication, corporeal narratives, and hybrid permutations. Thus, each of these turns is particular to its field, yet such common interest in narrative emphasizes its importance in expressing and structuring discourse, identity, and experience.

Narrative medicine arises 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. With writings on illness narratives, pedagogy, and ethics, the volume explored the myriad ways in which experiences of illness and care unfold in narrative terms and the implications for clinical practice, reflecting a rich history of such work. The field reached a critical point of articulation and development at Columbia University in New York with Rita Charon and colleagues’ scholarship and implementation in a range of contexts, including the medical school curriculum. Charon, whose 2006 *Narrative Medicine: Honoring the Stories of Illness* is a canonical work in the field, was joined at Columbia by literature and film scholar Maura Spiegel, philosopher Craig Irvine, physician-scholar Sayantani DasGupta, psychoanalyst Eric Marcus,

fiction-writer David Plante, and scholars Marsha Hurst and Rebecca Garden, among others. Sharing an interest in healthcare-themed literature with “Literature and Medicine”, the scope of enquiry broadens to study the narrative structure of works of art addressing a wide spectrum of topics, with “texts” reflecting the range of postclassical narrative theory: stories expressed in the body, in silence, in dialogue, graphic novels, oral history, and technology, alongside more traditional literary genres. Utilizing a variety of techniques, narrative medicine emphasizes the importance of developing narrative competence and explores its relevance to the health care setting. One of the distinctive practices developed by the Columbia practitioners is a workshop method of close reading, prompted writing, and dialogue, which is described and discussed below.

Close Reading in Practice

Close reading is central to narrative medicine: skilled attentiveness to a text, with particular interest in the form of an account. The act of reading in this sense parallels the act of listening, and by learning and practicing narrative competence we may offer better care and understanding. As Charon (2006: 107) explains, a physician

must be prepared to comprehend *all* that is contained in the patient’s words, silences, metaphors, genres, and allusions. Listening and watchful clinicians must become fluent in the tongues of the body and the tongues of the self, aware that the body and the self keep secrets from one another, can misread one another, and can be incomprehensible to one another without a skilled and deft translator.

A narrative medicine workshop dedicated to honing narrative competence may take various forms and occur in a range of contexts; it may include health care students, nurses, physicians, persons experiencing illness or disability, or another type of group.

Taking the example of clinicians reading and discussing a poem: the group may first read the poem aloud together, perhaps twice, listening for and discussing its syntax, details, and nuance, its cadence and silences, its narrative voice, its arc. A trained facilitator often guides the reading and discussion, encouraging participants to heed their own affective responses while simultaneously engaging and honing their analytic faculties to better understand the work. The piece under discussion may or may not explicitly address themes of illness. A group of clinicians often finds that non-medical topics prevent them from slipping into a familiar mode of analysis and diagnosis; the effect can be both unsettling and generative, and inevitably the discussion will return to health care, but with a different valence. Through close attention to detail, participants become aware of the ways in which the work elicits emotional and intellectual reactions, and the group typically experiences a variety of different responses. Such diversity can be surprising and revelatory, and readers must learn to sit comfortably with multiple perspectives and to tolerate ambiguity.

Although the tools of narratology and literary theory are operative in such discussions, technical terminology is often de-emphasized, particularly in an introductory workshop. A facilitator trained in literary criticism and theory may prompt a group of physicians to consider concepts arising from critical sources—such as French narratologist Gerard Genette’s distinction between story, narrative, and narration, or Russian literary critic Mikhail Bakhtin’s conception of chronotope, describing the interwoven aspect of time and space in literature—all without necessarily using such terms nor referencing the theorists. This practice certainly varies, and many narrative medicine workshops and seminars will explicitly invoke and study the critical tradition, but some groups may be unlikely to embrace a corpus of

unfamiliar technical terms. Broadly speaking, the pedagogical approach is more progressive than didactic, nourishing a rigorous collaborative interpretive process. Some facilitators may de-emphasize the author's biographical circumstances in order to avoid the presumption of a singular interpretation (what New Critics termed the "intentional fallacy"), while other discussions will take as their starting point a work's social, cultural, racial, and political context, the ways that it reflects and addresses specific historical conditions. In this sense the range of practices reflects the heterogeneity of contemporary critical discourse, which we will explore further below.

Following upon a discussion of the literary work, the group may be offered a short writing prompt and a brief amount of time in which to write—perhaps five minutes. The prompt often bridges the themes of the piece under discussion with individual reflections and experiences. For example, after discussing Elizabeth Alexander's (1997: 60) prose poem "Haircut," which describes a visit to a Harlem hair salon and includes the line, "What am I always listening for in Harlem?"—the group may be asked to write, beginning with the phrase: "What am I always listening for . . ." Typically many participants share what they have written, and then the group discusses the responses with close attention to form, structure, detail, and so forth, practicing the tools of narrative competence. The text and prompt must of course be crafted with sensitivity to context and with respect for participants' privacy and the operation of hierarchy and privilege within the group. Such an exercise calls upon interpretive and creative capacities that in many cases have long remained dormant.

How does this practice affect medical decision-making? The combination of close reading, writing, and discussion echoes the "different movements within clinical telling and listening" articulated by Charon (2005) as attention, representation, and affiliation: *attention*, as a form of listening and understanding, is reciprocally nourished by the receiver's attempt to formulate and *represent* what she has heard through a process such as writing, and both contribute to greater *affiliation* between teller and receiver. In the clinical context attention often takes the form of a physician's receptive and focused listening to a patient's account; representation may consist of the clinician's act of reflective writing about the experience, which then nourishes the quality of attention she is able to offer, thus enriching the affiliation between doctor and patient and improving diagnosis and treatment.

In the example of a group of clinicians in a narrative medicine workshop, the poem and discussion may offer specific insights informing medical decision-making and treatment, such as greater awareness of a patient's particular cultural context or of the clinician's own presumptions and projections. Through the act of inhabiting another point of view—both in the literary work and in the discussion of participants' different responses—a clinician may become more adept at imagining various perspectives. And by honing narrative competence through the triad of attention, representation, and affiliation, clinicians approach the care of the sick with greater awareness of stories' structure and import. The practice, too, offers an opportunity for clinicians to reflect upon their own experiences and to nourish—or in some cases revive—the humanistic basis of health care, and it notably contributes to greater collegiality and inter-professional collaboration as well.

Charon (2006: 177) tells the story of a new patient in her internal medicine practice and the ways in which she employs narrative medicine techniques to improve clinical care:

A 46-year-old Dominican man visits me for the first time, having been assigned to my patient panel by his Medicaid Managed Care plan. He has been suffering from shortness of breath and chest pain, and he fears for his heart. I say to him at the start of our first visit, "I will be your doctor, and so I have to learn a great deal about your body

and your health and your life. Please tell me what you think I should know about your situation." And then I do my best to not say a word, to not write in his medical chart, but to absorb all that he emits about himself—about his health concerns, his family, his work, his fears, and his hopes. I listen not only for the content of his narrative but also for its form—its temporal course, its images, its associated subplots, its silences, where he chooses to begin in telling of himself, how he sequences symptoms with other life events. After a few minutes, the patient stops talking and begins to weep. I ask him why he cries. He says, "No one ever let me do this before."

In this example, Charon exhibits a form of *attention* that her patient—who she calls Mr. Ignacio Ortiz—had not experienced in a clinical context. She then writes about the experience and shares it with Mr. Ortiz (who also grants permission for its publication), thus *representing* it, resulting in heightened *affiliation* between the two. Charon describes the complexity of Mr. Ortiz's health concerns, including depression, joint pain, cardiac disease, and difficulty working, as well as her commitment to listen for his physical symptoms as well as his "story of himself." When she refers him for specialized cardiac care, his willingness to trust and accept treatment is strengthened by the manifest affiliation between the two. When she attempts to discern the complex relationship between his inability to work and support his family and his coronary artery disease, she sees them as part of an integral whole and deploys a keen attentiveness to the narrative form his experience takes. As she describes, such an approach toward receiving a patient's story does not necessarily take longer than a standard interview, but the clinician must be trained and willing to hear it with a nuanced appreciation for the import of its narrative structure alongside the factual data: "I try my best to register the diction, the form, the images, the pace of speech. I pay attention—as I sit there at the edge of my seat, absorbing what is being given—to metaphors, idioms, accompanying gestures, as well as plot and characters represented for me by the patient" (2006: 187–188). These narrative skills have a direct bearing on the clinical care Charon is able to provide as a physician.

There are many and varied forms of narrative medicine practice that engage clinicians and non-clinicians alike. Creativity, in various forms, is integral—clearing a space for a participants to exercise and express the imagination. The "Parallel Chart," another formulation of Charon's, encourages health care students to write reflective notes about their clinical experiences, complementing the rubric of a standard H&P (history and physical examination) or SOAP (subjective, objective, assessment, and plan) note. A graduate-level seminar may combine the workshop experience with readings in literature and philosophy, while a medical school seminar or patient group may study thanatology or visual art. Film is a particularly rich medium for exploring the effects of narrative; as literary and film scholar Maura Spiegel and psychologist Arthur Heiserman (2006: 464) explain, "movies can light up parts of ourselves that have been dark for awhile," and a film prompts the viewer to engage in a way that evokes Arthur Frank's description of "thinking with" stories.

Illness and disability narratives, too, are an important area of study, from published memoirs to oral history to spoken word, with attentiveness to the operation of privilege and disenfranchisement: how might we understand "contested narratives," and how to interpret the role of silence? Does a category such as illness or disability narratives risk perpetuating a reductive pathologizing lens? In this sense the field is continually engaged in a dynamic process of interrogating the terms of health care, their implicit ideology and effects, as well as its own premises. It is, then, particularly important to situate the field, to explore its critical roots and context.

Critical Topography

True to the breadth of its practices and its interdisciplinary character, narrative medicine draws upon a variety of literary and philosophical schools of thought. Just as our account of its genealogy is necessarily selective, any map of its critical topography will represent a particular (and necessarily partial) narrative, privileging certain perspectives and eliding others. We will endeavor to navigate portions of its terrain, traversing some paths and—given the constraints of an introductory essay—merely nodding toward many essential areas.

The practice of close reading, integral to the field, has roots extending to exegesis of sacred texts, and enters into the tradition of literary theory and criticism with varied interpretations of what it entails, how it is situated, and what constitutes a text. Notably, the mid-century literary movement of New Criticism elaborated a focus on close reading of literary works, particularly poetry. Drawing upon and responding to British thinkers such as I. A. Richards, American writers and critics including John Crowe Ransom, T. S. Eliot, Robert Penn Warren, and Cleanth Brooks encouraged close study of a poem or work of prose as an entity expressing a type of organic harmony—Brooks likened the beauty of a poem to the unity of a flowering plant, including roots, stalk, and leaves. The methodology of New Criticism offers tools for formal explication of the structure and operation of a work, including its paradoxes and tensions, the relationship between the literal and the figurative, and so forth. However, following Brooks's metaphor, meaning does not quite extend to the *soil* of the plant, as interpretation is largely detached from historical context, the intention of the author, and the response of any given reader. While such a-historicism is, now, itself an historical chapter in mid-20th-century academic discourse, the practice of close reading has remained essential to literary study through the passage of many different models of criticism and theory.

As Rita Felski (2008: 52) describes, “Academic fashions may come and go, but a sharply honed attentiveness to nuances of language and form is still held, by most scholars and teachers of literature, as an indispensable sign of competence in their field.” Narrative medicine draws upon this tradition, asking how we may attend closely to the form of a text, slowing down to see what is at work in its operation. When a group lingers over three lines in a poem, discussing the resonance of particular words or a subtle shift in narrative voice, we become attuned to the operation of language in a different register. Such awareness informs our capacities as readers and as listeners. We may emerge with a different understanding of the metaphors employed in speaking about illness experiences, their evocations and significance. We may also hone our sensitivity to the way a narrative voice is figured, noting with fresh awareness the *lack* of a first-person narrator in a standard clinical or scientific account and the import of such rhetorical choices in framing medical and ethical decisions.

Fortunately, many modes of literary criticism offer direction in practicing close reading with attentiveness to different dynamics of a creative work and its context. For example, Derridean Deconstructionism analyzes a text (nearly infinitely broadly understood) as a series of unending signifiers; language is also, in this view, laden with hierarchical terms that can be exposed through close reading and synthesized in a new form encompassing unending interplay, eternally resisting closure. New Historicism considers the exchange between culture and literary works, emphasizing historical context and the ideological import of any form of discourse—in this sense, exploring the soil of the plant, the setting that is discounted in New Criticism's model of formal “unity.” And, admitting another critical element, reader-response theory stresses the importance of the reader—to belabor our analogy, the *beholder* of the beautiful flowering plant—and her role in co-creating meaning, bringing her own memories, associations, thoughts, and feelings to bear on a particular text. Scholars such as Norman Holland, Louise Rosenblatt, Stanley Fish, and Roland Barthes advance different models of

reader-response theory, and the school of criticism contains a range of perspectives on the locus of meaning-making, from underscoring the way a given text provokes certain reactions to accentuating the singular response of each particular reader.

A narrative medicine workshop or class setting draws upon a breadth of critical perspectives, an approach that highlights the contingency of any given school of thought. In particular, readers are encouraged to consider the means by which their reactions to a complex artistic work are activated, including the role of socio-historical context and individual identifications and projections. Through close reading and discussion of a literary work and of the group's prompted writing, readers learn to acknowledge the particularity of any given response and to recognize the range of different understandings. Such revelations are experiential and quite potent; they cannot be conveyed with the same effect through a lesson in literary criticism or cognitive science. A workshop participant comes to perceive her own role in a different and more nuanced fashion and—critically—applies that understanding to *listening*. For just as the reader of a text participates in meaning-making, the listener, too, co-constructs meaning with the teller of an account. And just as reader-response critics vary in their view of the relationship between text and reader, we may also ponder a range of possible relationships between teller and listener. When a person gives an account of a bodily experience to another—such as a patient describing his pain to a doctor—how is meaning constructed? To what degree does the listener bring her own associations to bear on what she hears? As a clinician becomes aware of the ways she is *reading* the stories told in language and in the body—how she is part of the meaning-making process—she attends with humility and care, strengthening both efficacy and affiliation.

Considering the physician who listens closely to her patient's account of pain, we may ask if she can ever *fully* understand another's experience, or if such a presumption may be incorrect and even appropriative. As philosopher Elaine Scarry (1985: 4) describes, physical pain is characterized by its intrinsic "unshareability" and "resistance to language." Beyond the experience of pain, we may also consider whether we can ever empathize (a contested term in the health humanities fields) with one another's experiences, or if we remain in some sense opaque to one another. Although this perspective may seem defeatist, such opacity to oneself and among persons can serve as the very basis for ethics, as Judith Butler (2005) describes in *Giving an Account of Oneself*, drawing upon philosophers such as Nietzsche, Hegel, Adorno, Foucault, Levinas, Hegel, and Cavareto. In particular, philosopher Emmanuel Levinas emphasizes the radical unknowability and primacy of the Other—an otherness that calls me to care for him—as the foundation for ethical action. In contrast to this alterity, Levinas describes the way in which I also possess a "totalizing" impulse to understand and assimilate the world in my own terms. As philosopher Craig Irvine (2005) describes, health care embodies this Levinasian paradox: it is a response to the fundamental call to care for the Other, yet medical science enacts the drive to circumscribe the world into rational classification. In Irvine's analysis, literature—in its capacity to represent experience—mirrors the way medicine inevitably reduces and systematizes. Thus it *exemplifies* this objectifying stance while also nourishing critical thinking, which enables it to play a vital role in health care education.

In considering such a view of alterity we bring a particular humility to the act of listening—see Sayantani DasGupta's 2008 discussion of "narrative humility"—and this awareness underscores the importance of attending to one another with subtlety and skill. Such competency proves particularly invaluable in health care, for despite its dogged positivism, medicine is steeped in stories. Comparing the diagnostic process to a detective's reconstruction of a crime, Kathryn Montgomery Hunter (1991: 25) likens it to a Sherlock Holmes mystery: "Like the master, the physician uses narrative first as a means of organizing the details that with luck and careful thought will flower into a testable generalization and then to demonstrate the accuracy of that generalization in the chronological chain of its

details." Critical to the diagnostic process, too, is a recognition of the importance of a patient's account. As Greenhalgh and Hurwitz (1998: 6) describe, "The narrative provides meaning, context and perspective for the patient's predicament. It defines how, why, and in what way he or she is ill. It offers, in short, a possibility of *understanding* which cannot be arrived at by any other means."

A growing interest in illness and disability narratives honors such experiences and accounts well beyond the sphere of diagnosis and treatment, and narrative medicine joins with scholars in literature and the arts, sociology, and ethnography to explore the resonance of these stories. For example, psychiatrist and anthropologist Arthur Kleinman conducts an ethnographic investigation of narratives and signs of illness, with a particular emphasis on stigma and its role in healthcare. Making the distinction between *disease*, understood as the medicalized disorder, and *illness*, elaborated as the "innately human experience of symptoms and suffering" embedded within culturally specific normative standards of bodily experiences, Kleinman (1998: 3, 10) also suggests guidance for clinicians in offering "empathic witnessing of the existential experience of suffering." And drawing upon narratology and sociology, scholars such as Anne Hunsaker Hawkins (*Reconstructing Illness*) and Arthur Frank (*The Wounded Storyteller*) offer analysis and structural typologies of "pathographies," exploring the effect of prevailing cultural narratives and objectifying healthcare practices on illness experiences.

Scholarship about illness and disability narratives often bridges analytic, affective, and corporeal understandings—Frank, for example, describes a distinction between thinking about a narrative at a critical remove and "thinking with" a story, allowing it to touch and resonate with one's own experience. Along with scholars such as Havi Carel, Kathlyn Conway, S. Kay Toombs, and others, Frank also includes personal accounts of illness in his scholarship, breaching the passive or impersonal academic voice to explore the relationship between lived experience and the various means we use to understand it. At the same time, scholars such as John Hardwig question the putative authority of memoir and autobiography, and—broadly speaking—late-20th-century literary criticism expresses a deep-seated wariness of the effects of such stories' purported access to the unmediated experience of their authors. Recent scholarship by thinkers such as Rita Felski and Ann Jurecic seeks to resuscitate the importance of such works while heeding and responding to the critical tradition.

Positioned at this intersection of storytelling, identity, embodiment, and critical enquiry, narrative medicine explores and interprets the ways in which stories both reflect and structure experiences. Such a project of narrative hermeneutics (a formulation emphasized by Jens Brockmeier, among others) draws upon the philosophical tradition of Heidegger, Gadamer, and Ricoeur to explore the notion of "narrative identity," the ways in which we both construct and are formed by narratives. Narrativization is here understood as an integral component of experience—we are always already embedded within a range of stories—rather than as a descriptive postscript. Moreover, the process of forming and understanding narrative meaning is an ongoing and sometimes disruptive process. For example, invoking the work of canonical symbolic anthropologist Clifford Geertz, Anna Donald (1998: 22) describes the ways in which illness experiences are often characterized by conflict over contested narrative understandings and social constructions: a particular disease has a different etiology and resonance if one is informed by traditional Chinese medicine, Western medicine, or various specialties within these disciplines; furthermore, it carries different metaphorical and historical associations in different cultures (notably critiqued by Susan Sontag in *Illness as Metaphor*). Jerome Bruner (1987: 708) develops this perspective as well, exploring the ways in which narratives "become so habitual that they finally become recipes for structuring experience itself, for laying down routes into memory, for not only guiding the life narrative up to the present but directing it into the future."

Drawing upon the phenomenological tradition, corporeal narratives become vital to the interpretive project, offering an antidote to Cartesian mind-body dualism. Indeed, understanding the stories told by the body has long been integral to medical practice, from Galen to Madhava-kara, from Hildegard of Bingen to Elizabeth Blackwell to Atul Gawande—and reaffirming and expanding the scope of such narratives becomes an integral part of the field. (See Chapter 42 for an elaboration of phenomenology and narrative hermeneutics in medicine.) Also critical to our understanding is continued attentiveness to the role of stories in cultural discourse, reflecting and affecting the operation of power and privilege. Informed by and participating in scholarship and activism in disability studies, LGBTQ studies, critical race theory, and other disciplines, narrative medicine explores the means by which certain narratives silence and disenfranchise individuals and groups as well as the possibility for stories to operate as a powerful tool of advocacy for social change. As Hilde Lindemann Nelson (2001) describes, “master narratives” may perpetuate detrimental identities—often internalized by oppressed individuals and groups—against which counterstories offer the possibility of “narrative repair.” For example, according to Nelson, the “Clinically Correct” master narrative of trans* identity is one that understands a trans* person as passing or not passing as a particular gender (both before and after “transitioning”), thus perpetuating a gender binary; furthermore, it is reliant upon a pathologizing medical model. Alternative stories reframing such gender categories and affording greater personal determination without prejudice are, as Nelson argues, critical to improving the moral agency of and respect toward affected individuals and groups (2001: 125–135). Thus narrative becomes vitally important in understanding and addressing marginalization of particular groups within society.

Conclusion

Narrative medicine occupies a dynamic and evolving terrain, drawing upon and informing many disciplines. Its scope is global, with clinicians and scholars from many regions around the world working at this nexus of clinical care and the humanities. The field has a particular influence on health care education—at Columbia University College of Physicians and Surgeons in New York, for example, it is an established part of the required curriculum—and many programs turn to the field in order to strengthen humanistic education and address required competencies in inter-professional collaboration, emotional intelligence, cultural sensitivity, and listening skills. A growing body of scientific literature demonstrates that reading literary fiction improves theory of mind and that narrative medicine interventions advance clinical efficacy and humanistic care. And as we continue to address pervasive issues in public health and disparities in access to care, the field’s focus on the operation of power and privilege in narratives offers an important perspective and set of analytic tools.

In addition, the field offers a significant corrective to the rule-based principlism of bioethics articulated by Beauchamp and Childress; emphasizing the particularity of any given case/story, it joins casuistry and narrative ethics—with notable contributions from Richard Zaner, Tod Chambers, Anne Hudson Jones, Hilde Lindemann Nelson, and many others—to approach ethical questions and medical decision-making with a critical *literary* understanding rather than a normative approach. In its emphasis on relationality and context, too, the field challenges the pervasive emphasis on “autonomy” in bioethics. It also offers a meaningful interdisciplinary complement to “evidence-based” medicine; in this context it is sometimes termed “narrative-evidence-based medicine”—honoring different forms of evidence such as illness narratives, and demonstrating the ways in which medical science is itself narrative in nature, bound by its own set of rhetorical and epistemological models.

Positioned at the nexus of medicine, literature, philosophy, and many other discourses, narrative medicine seeks to bring such trans-disciplinary understanding to bear on clinical care,

and to continue the rich and complex enquiry into our understanding of the stories we tell ourselves and one another.

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Further Reading

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- Charon, R., DasGupta, S., Hermann, N., Irvine, C., Marcus, E., Rivera Colón, E., Spencer, D., & Spiegel, M. (2017) *The Principles and Practice of Narrative Medicine*. New York: Oxford University Press. (Elaboration of theoretical foundation as well as practical methodology in narrative medicine, co-authored by faculty members in the Program in Narrative Medicine at Columbia University)
- Jones, E.M. & Tansey, E.M. (Eds.) (2015) *The Development of Narrative Practices in Medicine, c. 1960–c.2000*. Queen Mary, University of London, London. Available from: <<http://wellcomelibrary.org/player/b22674871#>> [7 June 2015] (Transcript of “Witness Seminar” including many key figures in the field discussing the origins, development, principles, and practice of narrative medicine)
- Jurecic, A. (2012) *Illness as Narrative*. Pittsburgh: University of Pittsburgh Press. (A very thoughtful discussion of the genre of illness narratives, including its treatment in academic discourse and detailed study of several examples)
- Lewis, B. (2011) *Narrative Psychiatry: How Stories Can Shape Clinical Practice*. Baltimore: The Johns Hopkins University Press. (A valuable application of narrative medicine principles in a psychiatric context, including an astute review of the field's history and scope)