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Narrative Medicine

The Book at the Gates of Biomedicine

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The Book at the Gates

Once upon a time, a powerful enclave was settled and built: the Fortress of Western Medicine. With a history stretching back to Galen and beyond, the Fortress was dedicated to the advancement of medical knowledge and the care of the sick. In service of this goal, it has, over time, built ever-stronger walls around its perimeter, strengthening its understanding, methods, and exclusivity. Those who seek to enter its gates must pass through a series of challenges testing mind, body, and spirit. They must also absorb a vast store of information and learn a new language—"an arcane lingua franca that sits atop a Greco-Latin foundation nowadays opaque even to many of its own users," as Suzanne Fleischman describes (1999, p. 19). This specialized dialect is incomprehensible to the untutored outside the gates, known to the Fortress's citizens as "patients," derived from the Latin *patiēns,* able or willing to endure or undergo, capable of enduring hardship, long-suffering, tolerant; and the ancient Greek πήμα, suffering.

As the tools of the Fortress have grown in strength, so have its walls grown taller, and it has built stone pathways upon which its inhabitants walk. It proclaims its vision to be objective and neutral, free of the frailty and subjectivity of suffering human subjects, and largely confines its training to the biomedical sciences.[1] Yet the seemingly insurmountable divide of the enclave's barriers—alongside its increasing specialization and use of powerful technologies that have wrought astounding advances in medical treatment—has long threatened to irrevocably sever its practices from its humanistic substrate, the common soil subtending the Fortress and the encircling lands. Indeed, many contend that the near-exclusive emphasis on pathophysiology predicated upon a Cartesian mind–body split has resulted in "an amputation

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of the concept of humanity with which medicine does its job," as neurologist Antonio Damasio describes (1994, p. 255). Or as philosopher Drew Leder puts it: "Physicians have searched for an ideal of perfect presence—the immediate gaze, the unambiguous number. Yet this has led medicine away from the very real presence upon which it is founded: that of the living patient" (1990, p. 21).

Commensurately, while medical science advances dramatically—to the great benefit of a great many—the reductive biomedical focus is such that "patients" outside the gates have become discontent, subject to objectification, bureaucratization, and specialization. Meanwhile, many on the inside have become increasingly estranged from their own humanity, suffering high rates of attrition and even suicide. In response, some physicians pen accounts of the transformative journey into the city and its attendant alienation and hardships. On the covers of these memoirs are typically images of the city's inhabitants behind masks, or in fragments, not showing their faces. They attempt to become storytellers, to rejoin the pieces of their own humanity, to tell the story of the person "behind the mask." Yet the mask—and the wall—remain (Spencer, 2021b).

Those outside the gates have attempted to breach the barriers as well, often joining with allies on the inside to try to restore greater humanity to medicine. Some have hazarded combinations of different forms of knowledge to wedge open the doors. In the United States, for example, psychologists and sociologists pleaded the relevance of their knowledge to biology, amalgamating the three to form the biopsychosocial model and lobbing it at the gates. Those advocating oversight of clinical and research ethics forged the interdisciplinary field of bioethics. Those advancing humanistic care of the dying created the hospice movement, and those wishing to center care on the persons needing care launched patient-centered care and the patients' rights movement. Some of these efforts penetrated the enclave and altered its practices. Yet even as fervent and plaintive voices sounded the alarm from the inside—echoing physician Francis Peabody's 1927 exhortation 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" (p. 882)—the walls of the Fortress have grown ever sturdier.

Toward the close of the 20th century, a small but impassioned group gathered on either side of the gates bearing an offering in the form of a Book. "Doctors," they sang to the city's inhabitants, "a gift for you. Look inside, where you will find thousands of years of stories—and in close reading of

these stories, we offer a method. Better readers make better doctors, and so in gaining 'narrative competence,' this method will improve and enrich clinical care."

There were many skeptics in the citadel, and many who ignored or ridiculed the gift. But finally the great gates creaked open and the Book was pulled inside. And this is narrative medicine.

The Narrative Turn

Narrative medicine emerged as a phalanx (derived from one sense of the ancient Greek φαλαγγ-, φάλαγξ, "body of heavy-armed infantry drawn up in close order") of would-be healthcare reformers gathered at the gates of the Fortress. It was also a phalanx (from another sense of the same root, "bone of the finger or toe") of the so-called narrative turn in the humanities and social sciences (OED Online). For in the wide country outside the Fortress in the late 20th century, many disciplines found renewed focus on the importance and pertinence of narrative. Narrative medicine is a notable exemplar of the narrative turn—and, more specifically, as we shall see, of narrative hermeneutics—put into practice. Indeed, its foundational definition is as a method of clinical practice informed by narrative skills, recognizing and emphasizing the intrinsically narrative nature of healthcare. Physician and literary scholar Rita Charon, who named and developed the field at Columbia University in collaboration with an interdisciplinary group of scholars and practitioners, defined it as "medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" (2006, p. vii). It has also evolved to become a transdisciplinary health humanities field of inquiry in conversation with literary criticism and theory, race and gender studies, creative expression, philosophy, and disability studies, among other fields, exploring the nexus of medicine and the humanities and striving toward social justice in healthcare, with an enduring focus on narrative.

The many forms and detours of the narrative turn are reflected in narrative medicine and help to illuminate the field's core principles and practices. For example, as Matti Hyvärinen describes, the first curve of the narrative turn arose in literary studies in the 1960s with Todorov's "scientific narratology" and an interest in, as Kreiswirth puts it, "narrative for its own sake" (2010, pp. 72–73; Kreiswirth, 2005, pp. 377–378). Hyvärinen quotes Marie-Laure

Ryan: "It was the legacy of French structuralism . . . to have emancipated narrative from literature and from fiction, and to have recognized it as a semiotic phenomenon that transcends disciplines and media" (Hyvärinen, 2010, pp. 72–73; Ryan, 2005, p. 344). Correspondingly, a central tenet of narrative medicine is that narrative skills are often best achieved by studying *narrative for its own sake*, as a semiotic phenomenon present in all facets of our experience. In this sense it distinguishes itself from the closely related field of "literature and medicine," which advances the analysis of literary works with a topical focus on healthcare, illness, and disability. While narrative medicine does embrace such study as well, the field's signature workshop methodology often emphasizes close reading of texts that are *not* explicitly healthcare or illness-themed (Spiegel & Spencer, 2017a, p. 16).

In such a narrative medicine workshop, a small group may gather to practice close reading of a creative work selected for its richness and complexity. The experience is designed to be inclusive and exploratory rather than didactic, examining the piece's narratological features such as voice, tone, temporality, and structure and the ways they inform the reader's experience and interpretation of the text, seeking to understand the context of readerly responses. It is not a strictly structuralist narratology in which "the sense-making subject and related notions such as intentionality, experience, and existence" are elided, but a more hermeneutically oriented approach, "conceptualiz[ing] narrative in terms of a subject who strives to give meaning to his or her experiences, while at the same time radically decentering—that is, socializing and historicizing—this subject," as Brockmeier and Meretoja describe (2014, p. 4). After discussing the work, the facilitator may then offer a brief writing prompt, followed by individuals sharing their writing (if they wish) and the group responding, building trust and often expressing emotion while continuing to hone the tools of narrative analysis (Spiegel & Spencer, 2017b). In the process, participants are invariably exposed to a variety of different readerly interpretations from fellow members of the group. And while the facilitation is grounded in close reading, it often draws on a breadth of critical perspectives, from reader-response theory to new historicism (even if such approaches are not explicitly named) traversing a heterogeneous array of explicative rubrics (Charon, 2017b, p. 164; Spencer, 2017, p. 379). Thus the interpretive process is highlighted at every level: that of the individual reader, the group, the theoretical framework, and the dynamic interplay between these registers. In the foundational conception of narrative medicine, clinicians then integrate these narrative skills into their praxis. As

Charon describes, "narrative competence permits caregivers to fathom what their patients go through, to attain that illuminated grasp of another's experience that provides them with diagnostic accuracy and therapeutic direction" (2006, p. 11). To gain entrance into the Fortress of Medicine, the Book must offer an efficacious clinical methodology, and here the premise and promise is that "good readers make good doctors" (Charon, 2006, p. 113).

Turning back to the narrative turn: another of its characteristics reflected in narrative medicine is a recognition of the ubiquity of narrative. Hyvärinen quotes Roland Barthes on the extent to which narratives occupy "a prodigious variety of genres, themselves distributed amongst different substances—as though any material were to receive man's stories. . . . narrative is present in myth, legend, fable, tale, novella, epic, history, tragedy, drama, comedy, mime, painting . . . stained glass windows, cinema, comics, news items, conversation" (Hyvärinen, 2010, p. 73; Barthes, 1982, pp. 251–252). Speaking to this omnipresence, narrative medicine reads for narrative in a wide array of texts: from the clinic note to the body language of a person learning of a new diagnosis; from the structure of a sonnet to the lacunae in an account of physical pain. An additional facet of the narrative turn, particularly in the social sciences, is, as Hyvärinen describes, an emphasis on privileging the voices and stories of those who have been historically suppressed and disenfranchised. Correspondingly, in narrative medicine an attentiveness to power structures is ever-present, with an abiding commitment to social justice and narrative ethics. A central priority is to explore ways that tools of narrative understanding abet equity and anti-racism in healthcare, raising the voices of those who have been marginalized and oppressed. Yet another critical emphasis of the narrative turn in the social sciences is the metaphor of *life as narrative*. As Hyvärinen notes: "Together these two promises—to offer politically alternative stories, on the one hand, and to offer an existentially new vision to human life, on the other—helped to create the atmosphere of a new intellectual movement. Within this perspective, the story of the narrative turn itself was sometimes understood as a quest narrative" (2010, pp. 75–76).

In narrative medicine (which figures its own story as something of a quest narrative, a goal being to improve the practice of medicine), the understanding of *life-as-narrative* is quite resonant, understood as an instrument of empowerment. Here the arc from workshop text to considering narrative as a means of understanding lived experience recapitulates the existential turn of hermeneutics, wherein,

> akin to the shift in narrative theorizing from fictional, textual, and linguistic structures to general forms and practices of human action and interaction, hermeneutics changed: it transformed from understanding textual and linguistic meaning (the dominant endeavor in nineteenth-century hermeneutics) to a notion of understanding as a basic concern of human life, as an intrinsic component of our forms of life. (Brockmeier & Meretoja, 2014, p. 9)

In considering such existential dimensions, narrative medicine is largely aligned with the "strong narrative thesis," which, as Brockmeier explains, "exposes the world-creating qualities of narrative as a form of agency, a form we use in a wide spectrum of actions." In particular, *narrative agency* offers the possibility of action, as "the focus on narrative as a social practice turns people into protagonists—including oppressed, marginalized, and disadvantaged people who often have their rights and voices denied" (2015, pp. 123, 177). Thus scholar-practitioners in narrative medicine pose such questions as: How does illness or injury bring about a change in one's account of self? What informs the dominant narrative, and what tools might we use to recuperate interpretive prerogatives for our own lives? How might such tools help those occupying the patient role to forge a truly collaborative working partnership with those inside the medical gates?

As the narrative turn reaches many different disciplinary territories, one of the emergent questions pertains to *bodies*—to what extent narratives offer an understanding of our material existence. Again, here narrative medicine finds itself at the heart, if you will, of these debates, in dialogue with phenomenology and a range of disciplines exploring the somatic basis of narrative. For example, Anna Donald describes the ways in which "the symbolic/story-making process is not an abstract one that goes on somewhere in the intellect, or solely in the white and grey matter of the cortex. . . . in relay with the brain, narratives are processed and programmed into the rest of the body: the musculature and autonomic nervous system; that whole domain of feelings: of rage, of pain, of joy, the felt responses to information that we carelessly call emotions" (1998, p. 19). Another example is autobiography scholar John Paul Eakin's account of his own evolving understanding of narrative traveling "from text to body" as he read Damasio's *The Feeling of What Happens: Body and Emotion in the Making of Consciousness* in which, as Eakin describes, "narrative is biological before it is linguistic and literary" (2013, pp. 87–88; Damasio, 1999). He also quotes Barthes's proposal that "the

symbolic field is occupied by a single object from which it derives its unity" and that "this object is the human body" (p. 90; Barthes, 1974, pp. 214–215).

This very question of the proper scope of narrative is ripe fodder for debate in the land of narratology and beyond. Some contend that including the body under the aegis of narrative is an instance of "narrative imperialism," to use James Phelan's term for the purportedly "expansionist impulse by students of narrative to claim more and more territory" (2005, p. 55). Indeed, such imperialism has been imputed to the narrative identity thesis, which holds that narrative is, in Eakin's words, "not merely a literary form but a mode of phenomenological and cognitive self-experience" (2001, p. 113). Reacting to such perceived expansionism, Galen Strawson's influential "Against Narrativity" argued that the narrative identity thesis is both incorrect and harmful (2004). Moreover, Angela Woods has suggested that Strawson's critique of narrativity should prompt the field of medical humanities to consider the limitations of narrative, and the opportunities that lie beyond it (2011). However, in Eakin's response to Strawson in the pages of *Narrative*, he notes that Strawson "grossly undervalues the power of narrative not only as a form of self-representation but as an instrument of self-understanding." Furthermore, he adds, "What about the power of narrative to reveal the failings of particular narrative understandings of one's own experience?" (2006, p. 184).

Eakin's practical question brings us back to the Book at the gates—narrative medicine's self-definition as a method of clinical practice, offering the *utility* of attending to narrative in healthcare. We might add: *What about* the power of narrative to deepen mutual understanding and affiliation between patients and providers, thus improving clinical care? *What about* the power of narrative to illuminate the ways in which an individual might understand an illness experience—when, say, a dominant cultural narrative script is harmful or helpful, prescriptive or liberating?[2] And while we're at it, *what about* narrative attentiveness' capacity to highlight narrative framing, particularly in the context of the hegemonic discourse of biomedicine, which naturalizes its preferred forms of knowledge and rhetoric such that only that which originates in the Fortress is deemed evidential and objective? For these are crucial imperatives, and while Strawson critiqued the normative and ethical claims of the narrative identity thesis, the exigency propelling narrative medicine—which does, broadly speaking, embrace the narrative identity thesis and certainly the importance of narrative—is precisely a response to a normative and ethical crisis in healthcare. As it stands at the entrance to

the Fortress, it offers the Book—close reading of literature—as a powerful method, advancing narrative skill as a means of improving clinical care.

Method and Hermeneutics

The band of reformers at the gates seeks a way for the Book to penetrate the Fortress of medicine, and offering "narrative competence" as a useful component of clinical methodology is itself a practical method to achieve this goal. Yet as soon as the Book enters the enclave, out of its belly comes hermeneutics, for narrative is intrinsically interpretive. This is an understanding of "narrative as a hermeneutic practice in itself, a practice of meaning-making," as Brockmeier and Meretoja describe (2014, p. 2). Once inside, hermeneutics emerges not to destroy the Fortress but to enrich it.

The more instrumental methodological orientation—a technique of achieving "mastery" of narrative tools in order for the clinician to glean useful information about the patient's experience—and the more open-ended, reciprocal, hermeneutical aspects of narrative medicine continue to co-exist. As Camille Abettan describes, these aspects of narrative medicine can be understood in relation to Gadamer's distinction "between a methodic epistemological framework and a hermeneutical one" (2017, p. 180). In *Truth and Method* Gadamer elaborates the difference between the kind of empirically verifiable truth we seek in the sciences and the kind of truth that can be experienced through, for example, works of art. The former proceeds in accordance with rules, seeking definitive answers. And while there has been an effort to apply "scientific" methodology to the whole of human experience, Gadamer underlines the limitations of such an approach, describing *understanding* as a dialogic practice that does not follow a set of rules, nor does it presuppose that mastery is possible or desirable (Maplas, 2018). Indeed, the experience of art offers "the most insistent admonition to scientific consciousness to acknowledge its own limits," as Gadamer describes (2004, pp. xxi–xxii). Thus hermeneutics, in Gadamer's conception, is advanced in contrast to a more methodic undertaking:

> The hermeneutics developed here is not, therefore, a methodology of the human sciences, but an attempt to understand what the human sciences truly are, beyond their methodological self-consciousness, and what connects them with the totality of our experience of world. If we make

> understanding the object of our reflection, the aim is not an art or technique of understanding, such as traditional literary and theological hermeneutics sought to be. Such an art or technique would fail to recognize that, in view of the truth that speaks to us from tradition, a formal technique would arrogate to itself a false superiority. (p. xxii)

While narrative medicine is largely aligned with this hermeneutic orientation, a crucial part of its work is to continue to evince this very tension between a methodological ideal of clinical mastery—a utilitarian technique devoted to extracting meaning—and a hermeneutic emphasis on process, dialogue, and openness to others' stories, with an acknowledgment of alterity. For in so doing, narrative medicine appeals to the Fortress to interrogate the ways in which it *arrogates to itself a false superiority*, fortifying its walls and presuming that its methodic biomedical paradigm supersedes its humanistic calling.[3] And so to return to Eakin's questions about the function of narrative, we might add yet more questions, such as: *What about* the ways in which attentiveness to narrative in clinical practice draws attention to this very tension Gadamer articulates between method and hermeneutics? *What about* the potential benefits to healthcare in illuminating this tension?

On the methodic side, the pragmatism of narrative medicine's originary praxis is well articulated in Charon's early writing and her foundational 2006 *Narrative Medicine: Honoring the Stories of Illness*. Here she describes narrative medicine as "a very practical undertaking," for "literary methods are of tremendous practical use to us in medicine" (pp. 17, 54). Moreover, "the clinic becomes the literary scholars' laboratory, while their theories contribute to clinicians' daily work" (p. 109). The process of achieving clinical competence is the model for achieving narrative competence: "In the same way in which a medical student is trained to look at [X-ray] film quality, bones, mediastinum, heart, and lungs, readers can be reminded to consider explicitly each of . . . five textual aspects [of frame, form, time, plot, and desire]" through a "reading drill" (p. 114). Better readers—of X-rays, literary texts, and patients' stories—make better doctors. Narratology is absorbed into the medico-scientific toolkit: "Today's narratively competent medicine. . . . relies on mastery of contemporary advances in literary studies, much as medicine's technologic competence relies on mastery of contemporary scientific studies" (2000, p. 26).

Such emphasis on clinical utility continues in Charon's description of the "parallel chart" exercise in which medical students write about clinical

encounters in ways the conventional medical chart does not allow. While this creates an opportunity to express affective responses to what are often existentially traumatic experiences with illness and mortality, Charon emphasizes the methodological benefit of such "textual work" as a component of clinical training over any sort of therapeutic benefit. As she explains: "I have come to make these distinctions for practical reasons. The death knell of any innovation in medicine or medical education is for it to be labeled 'touchy-feely' or 'soft' " (2006, p. 156). Efficacy is defined by the guardians of the Fortress, and since attending to emotion has historically not been, by their metrics, intrinsically valuable (despite the many studies documenting dramatic attenuation of empathy in medical school; despite the widespread issues with physician suicide and burnout; despite the fact that the *care* in *healthcare* is not just an act but an emotion, etc.), it could only enter the closely guarded gates of the medical school curriculum as a double effect of "mastering" textual skills insofar as they are understood as clinical skills. This methodical emphasis, again, is strategic and utilitarian. As Charon described in 2008:

> Narrative medicine from the start has been a very practical field, never theorizing outside a praxis, be it in patient care or medical education or doctorly reflection. We offer narrative skills to health professionals and students not as civilizing veneer—how cute, a doctor who writes poetry—but as means to increase their clinical effectiveness. Although one runs the instrumental risk of seeming to flatten the intrinsic value of reading and writing by virtue of focusing on the improvements in clinical performance that occur as a result of narrative training, we believe that this field has first to declare its usefulness within the clinical setting if it wants health professionals to make time for it and to choose it against all the other skills competing for time and effort. (pp. 26–27)

Yet while the Book at the gates declares its clinical utility in order to enter, hermeneutics has in fact been there in its belly from the start—the premise, as Brockmeier and Meretoja describe, that "human understanding is mediated . . . through sociocultural circumstances, history, and signs—particularly, language. Directly related to this claim is the interpretive imperative" (2014, p. 4). And as they point out, while Charon draws primarily upon her work as a clinician, her work contains "an amazing presence of

hermeneutic gestalts" (pp. 21–22). These include an emphasis on meaning-making, acknowledgment of alterity and the centrality of relationality, the call to understand illness experiences with a fluid interpretive approach, and recognition of a multiplicity of narratives and sources of authority. Indeed, Brockmeier has identified hermeneutics as one of the "background movements" of narrative medicine, describing its "underlying hermeneutic-interpretive operations" as "unfinished, and unfinishable, ongoing processes" (Jones & Tansey, 2015, pp. 33–34).[4]

Narrative medicine's utilitarian methodic emphasis and hermeneutical orientation co-exist. Referencing Gadamer's distinction, Abettan diagnoses the field with a purportedly unacknowledged and unresolved confusion, suggesting that its "self-understanding is currently hesitating between these two different epistemological frameworks" (2017, p. 180). As she describes, the tension between them "arises from the will of dealing with everything that escapes certainty in medicine, and the tendency to go on with an epistemological framework that has been elaborated in order to deal with what can be known with absolute certainty" (p. 189). And the problem, she maintains, is that the paradigms are incompatible. To take a medical analogy, I picture an Rh-negative mother bearing an Rh-positive child: the solution-oriented methodological orientation of "narrative competence" will generate antibodies to attack the certainty-averse hermeneutical baby it bears in its belly; conversely, the mother's instrumentalization of "narrative competence" is antithetical to little Hermie's raison d'être. The prescription for such a disease of epistemological incompatibility, Abettan suggests, is to clarify and resolve the tension and embrace narrative medicine's hermeneutical identity (p. 189).

While clarifying the tension between method and hermeneutics is indeed helpful, there is value in preserving it, for it exemplifies these very epistemological paradigms. Their co-existence is itself hermeneutical, as it *evinces* the contrast and *exposes* it to the citizens of the Fortress of Biomedicine. In narrative medicine, this dialectic between a more pragmatic methodical orientation and a more open-ended hermeneutical gestalt develops in a number of ways, including the following, which we will examine in greater detail: (1) questioning readerly roles and advancing humility, (2) questioning readerly roles in creative texts about illness and healthcare, (3) questioning the nature of reading and of the text, and (4) questioning diagnostic narratives through the phenomenon of "metagnosis."

Questioning Readerly Roles and Advancing Humility

One key means by which this tension between method and hermeneutics is enacted is vis-à-vis the foundational conception of doctor-as-reader. As Charon outlines, "the means the doctor uses to interpret accurately what the patient tells are not unlike the means the reader uses to understand the words of the writer" (2000, p. 24). Alongside such an analogy is, arguably, the presumption that the text is something that can be mastered; that the doctor-reader can, in Charon's words, "fathom the meaning embedded in experiences of illness or health" (1986, p. 73) or divine in a patient's story "that which is held, secretively, within its center" (1993, p. 91) just as she can divine evidence of disease process within an X-ray. Yet once such a methodic model for reading is proposed, a hermeneutical process embracing contingency and humility shows itself as always-already present—very much so within Charon's evolving formation as well—productively subverting any attempt at certainty.

Indeed, in tracing back the contemporary physician-as-reader model, we find that hermeneutics is present from its early conception, including an active interrogation of these very readerly roles. For example, in Stephen Daniel's 1986 "The Patient as Text: A Model of Clinical Hermeneutics," he draws the analogy between doctor/patient and reader/text: "If we take advantage of the insights gained from the interpretation of literary texts, perhaps we will be able to demonstrate to our medical colleagues how they, like literary critics, inescapably practice the art of interpretation every day. The meaning they find is the meaning of the individual human being who is the patient." Referencing the "medieval fourfold sense of scripture," Daniel harkens back to the roots of hermeneutics in biblical exegesis; the textual metaphor illuminates the ways in which "hermeneutics (i.e., the science and art of interpretation) lies at the heart of medical practice." This is understood as a *process*, for revelation only comes to "one who struggles continuously for a faithful reading of each fresh text presenting itself in everyday experience" (pp. 208, 200, 196, 208).

Also in 1986, George Rousseau, too, advocates for "the education of doctors in the interpretation of 'texts' so they can 'read' their obligatory ones: their patients." Yet he suggests that the patient-as-text metaphor is also productive insofar as it invites consideration of the ways in which it is *in*sufficient, and he cautions that "for all its good intentions," it also risks limiting its efficacy by "privileging the utilitarian goal over others" (pp. 176–177). Again, this

tension between methodic pragmatism and hermeneutics is present; moreover, the analogy quickly becomes more nuanced. Albert Carter III, also writing in 1986, explores the model of text/interpretation in the clinical encounter to sketch a more reciprocal exchange: "As the patient asks questions and comes to understand, imaginatively, the story being sketched, he or she becomes an active 'reader,' perhaps even a co-author." (p. 145). And in 1990, Drew Leder takes up the textual metaphor wherein "the physician interprets the 'text' of the ill person" and specifically characterizes it as a "hermeneutical enterprise" (p. 9):

> Modern medicine needs to awaken from its dream of a purified objectivity. This dream has served a positive function, spurring medicine on to awesome technological and conceptual achievements. However, such achievements can best be employed within a context of *hermeneutic humility*. For once it is recognized that interpretation cannot be expunged, we can ask how it may most effectively be assisted. The hermeneutic model thus poses a series of fruitful questions for future investigation: How can medicine achieve the ideal balance between its various texts? How can it maximize the interpretive modes it brings to bear, without sacrificing coherence? How can the art of clinical interpretation most successfully be taught? Might the humanities play a role in teaching hermeneutic skills? What of the balance of bedside apprenticeship versus classroom learning? And, perhaps most importantly: How can the ill person, both as text and cointerpreter, be restored to centrality in the clinical encounter? Unless we address such hermeneutical questions, the rapid growth of medical science cannot be put to best use. (p. 22; emphasis added)

These questions and cautions concerning the readerly role have accompanied the textual metaphor as it has evolved in narrative medicine and beyond. For once we conceive of a text, it invites consideration of the reader's stance toward the text, reflecting and refracting a legacy of calls for humility in healthcare. Indeed, humility was a recurrent theme for Sir William Osler—the so-called father of modern medicine—who in 1892 exhorted medical students to exercise the *Grace of Humility*: "In these days of aggressive self-assertion, when the stress of competition is so keen and the desire to make the most of oneself so universal, it may seem a little old-fashioned to preach the necessity of this virtue, but I insist for its own sake, and for the sake of what it brings, that a *due humility* should take the

place of honour on the list" (2001, p. 121; emphasis added). Evidently his insistence didn't bear much fruit, as more than a hundred years later, in Charon's *Narrative Medicine: Honoring the Stories of Illness*, she proposes that "what medicine *lacks* today—in singularity, humility, accountability, empathy—can, in part, be provided through intensive narrative training" (2006, p. viii). Leder's injunction to restore *hermeneutic humility* to modern medicine presages narrative medicine physician-scholar-activist Sayantani DasGupta's call for *narrative humility*, underscoring the ways in which "our patients' stories are not objects that we can comprehend or master, but rather dynamic entities that we can approach and engage with, while simultaneously remaining open to their ambiguity and contradiction, and engaging in constant self-evaluation and self-critique" (2008, p. 981). Here DasGupta draws on Tervalon and Murray-Garcia's advocacy for a self-aware *cultural humility* in place of cultural competency—understood as "an easily demonstrable mastery of a finite body of knowledge"—in medical education (1998, p. 118). Wardrope adds a plea for *epistemic humility* in healthcare as "an attitude of awareness of the limitations of one's own epistemic capacities, and an active disposition to seek sources outside one's self to help overcome these shortcomings" (2015, p. 350). Coulehan proclaims that in medicine's new professionalism, "unpretentious openness, honest self-disclosure, avoidance of arrogance, and modulation of self-interest must be included as integral parts of the picture. And, taken together, they constitute *humility*" (2011, p. 215; emphasis added). A study finds that *physician humility* correlates with self-reported patient quality of health and effective physician–patient communication; according to the authors, "the results suggest that humble, rather than paternalistic or arrogant, physicians are most effective at working with their patients" (Ruberton et al., 2016, p. 1138)! Moreover, Irvine and Charon take up the stance of *radical humility* in writing about narrative medicine in relation to ethics (2017, p. 125), and Charon emphasizes that narrative medicine's conception of the clinician trained in narrative skills includes acknowledgment of the alterity of the Other: "Not that you can nail what it is a patient means, but rather that you find yourself *humbly* in the face of something very complex, not totalizable, not reducible to anything, not paraphraseable—which holds a key of sorts to what might help the patient" (Levy, 2021, p. 35; emphasis added). The through line to this recurrent call for the *grace of*, *due*, *hermeneutic*, *narrative*, *cultural*, *epistemic*, or *radical* humility is, well, humility. The textual metaphor helps to illuminate this imperative,

as once we experience ourselves as readers—as occurs in the narrative medicine workshop setting—we are prompted to become mindful of the variability of interpretation and its ethical valence. The double effect of introducing textual skills into the Fortress is that it discloses such situated self-awareness, productively subverting the enclave's unhumble claims to neutral objectivity.

Another way of approaching such readerly humility is a recognition that the textual metaphor itself risks reifying the passive "patient" as text. Indeed, in response to Leder's 1990 paper, Baron cautioned that

> the metaphor of clinical work as textual explication . . . creates the expectation that there is a text somewhere to be found. Such an expectation invites doctors and patients to search for the text and runs the risk of conceptualizing patients as more static than they are. If one is to use the textual metaphor, one must appreciate the radical extent to which the clinical encounter is a mutually produced and shifting entity. The qualities of mutuality and indeterminacy are not those one usually associates with texts. One might ultimately be better served by a different metaphor based more directly on uncertainty. (1990, p. 25)

Philosopher Frederik Svenaeus, too, suggests that the textual metaphor does not speak to the dialogical character of the clinical encounter, as "this kind of hermeneutics is not a methodology of text reading, but an ontological, phenomenological hermeneutics in which understanding is a necessary feature of the being-together of human beings in the world" (2000, p. 185).

This very question of whether the metaphor is apt and how it should be understood becomes quite generative. In 1989 Charon points out that "the patient-as-text formulation . . . consigns the patient to the relatively passive role of serving up the story. The physician is in the active role, and the outcome of the reading seems to rely altogether on the powers of interpretation of the doctor" (p. 138). In 1993 she elaborates a dynamic, reciprocal model of co-authorship: "What, in fact, do doctors and patients do together but to create between themselves a many-staged narrative, sharing the roles of teller and listener, moving through a series of rhetorical strategies toward, ideally, accuracy and freedom?" (pp. 94, 87). Drawing upon perception and representation in the creative arts, she illuminates the ways in which "an ethos of reciprocity offers a radical alternative to the framework of unequal power or resources" in the clinical encounter,

inviting "a humble realization that no one understands what health *is* and a concurrent welcoming curiosity about one another's conception of how the body and speech and mind work" (2014, pp. S23, S21). Here the figure of reading helps to *illuminate* the shared hermeneutical complexity of the clinical encounter.

The caution to carefully consider the readerly role is present throughout as narrative medicine elaborates the textual metaphor, with an emphasis on hermeneutics. In the introduction to *The Principles and Practice of Narrative Medicine*, Charon offers an open, inclusive model: "All who seek care and all who seek to give care can unite in a clearing of safety, of purpose, of vision, and unconditional commitment to the interests of patients. This is the vision of narrative medicine" (2017c, p. 5). The principles and practices elaborated in this book are profoundly hermeneutical, welcoming all invested in healthcare to join the clearing, and resisting the certainty of closed methods and meanings. In describing a sample narrative medicine workshop, for example, Maura Spiegel and I explain that effective writing prompts "do not ask for an answer or an analysis but rather ask readers to look inward, to find a resonance with the text's ambitions and allow them to co-mingle with one's own memories and experiences" (2017b, p. 52). Here we elevate the importance of relationality and emotion and their intrinsic worth: "In narrative medicine the attention to character actions, nuances, how the story is told, perspective, temporal unfolding, tone, images, and the rest is in the service of having an experience as Dewey describes it, and, as he implies, of creating habits of mind to become more noticing (via aesthetic engagement) of the dynamics of one's own experiences—with patients, colleagues, and institutional structures" (2017b, p. 57). Crucially, the textual work of the narrative medicine workshop occurs in a dialogical group context, exemplifying the ways in which, as Svenaeus describes, *understanding is a necessary feature of the being-together of human beings in the world*. In writing about narrative ethics, moreover, Irvine and Charon describe the ways in which engaging with texts belies any illusion of a fixed meaning to be mastered, as when "one enters the narrative world of a text, one lets go of the conviction that a key to its meaning is to be found anywhere but in the experience itself of encountering it" (2017, p. 113).

Tracing the development of the textual metaphor, then, we find that it offers the opportunity to pose and explore generative questions about readerly roles and ethical responsibilities, which then bear upon healthcare.

Questioning Readerly Roles in Creative Texts About Illness and Healthcare

Once considering the textual metaphor, the roles vis-à-vis the text and our understanding of what constitutes the text become open questions. Here creative expressions about experiences of illness and healthcare—which are also of great interest to narrative medicine—can be particularly fruitful sites for exploring these questions.

One such example is Margaret Edson's 1995 play *W;t*, narrated by literature professor and Donne scholar Vivian Bearing as she navigates treatment for terminal cancer. In this portrayal the physicians are hubristic and unfeeling, torturing Bearing with a brutal yet futile chemotherapy regimen and seeing her only as a promising research case. They clearly didn't get the humility memo from Osler. Such illumination of the alienation and objectification endemic to contemporary healthcare resonated powerfully with theater audiences drawn from the "patient" multitudes—increasingly losing their patience—outside the gates of the Fortress (Charon, 2006, pp. 17–19), so much so that it was adapted as a 2001 film directed by Mike Nichols, starring Emma Thompson and Christopher Lloyd. This focus is characteristic of what Whitehead and Woods characterize as "first wave" medical humanities: "Operating within a series of binaries (patient/doctor, illness/disease, medicine/humanities), first-wave medical humanities aimed to produce a shift in clinical method toward attending to and interpreting patients' subjective experience," privileging "texts that provided a realist account of a particular medical condition. For the patient, narrative was seen to provide an effective vehicle for articulating illness, and to hold potentially transformative value" (2016, p. 4).

While many clearly welcomed such a corrective narrative, the play arguably offers more than the elevation of a (debatably) realist account of illness alongside some vigorous and sustained doctor-bashing, as it also invokes the textual metaphor, illuminating the question of *who* is doing the reading and interpreting. For example, Bearing describes and interprets the "dramatic structure" of Grand Rounds to the spectator of the play: "Full of subservience, hierarchy, gratuitous displays, sublimated rivalries—I feel right at home. It is just like a graduate seminar. With one important difference: in Grand Rounds, *they* read *me* like a book. Once I did the teaching, now I am taught." When the attending physician compliments the medical resident, Jason—who had taken Bearing's class on 17th-century poetry—on his

"excellent command of details" in presenting Vivian's case, she says to herself, "I taught him, you know" (Edson, 1999, p. 37). Later Jason describes her course as "more like boot camp than English class" and as "great training for lab research" (p. 76). Here reading and interpreting is applicable to both literature and the body, just as Charon's "reading drill" follows the process of learning to read an X-ray film (note the militaristic characterization common to both). Readers of Donne's "Holy Sonnets" and of cancerous tumors are similarly engaged in a hermeneutics of mortality. However, the physician-as-reader dominates in the hospital, and Vivian's readerly knowledge will not be heard by these clinicians.

Yet Vivian does not simply remain the passive "patient" text, for she is figured as the primary reader and interpreter of the play, as in the Grand Rounds scene, where she narrates her internal observations to the audience at the same time as Jason "presents" the case (i.e., Bearing's cancer) to his supervisor. In the script their respective readings of the events are juxtaposed in two adjacent columns. This format echoes Derrida's *Glas*, in which one column of texts addresses Hegel, the other Genet, producing what Martin Jay describes as "a double reading, which refuse[s] to resolve itself like a stereoscope into a single, three-dimensional image" (1994, p. 496). In *W;t* this recurrent double reading has the double effect of exposing the patient's "subjective experience" alongside the official clinical narrative and exposing reading *as such*. It suggests a recuperation of the hermeneutic role of the "patient," otherwise figured as the passive and patient text.

Unfortunately, here such hermeneutic empowerment is ultimately subsumed by the elevation of the lived experience of illness. In this respect the play reflects the priorities of first-wave medical humanities, but it needlessly derogates Vivian's privileging of the life of the mind and of interpretation, suggesting that wanting to "know more things"—whether it's textual hermeneutics toward a Donne sonnet or toward an insidious adenocarcinoma—is antithetical to emotion, kindness, and life itself (Edson, 1999, pp. 68–69). But this isn't true. It's not a zero-sum game. (Note to oncology researchers: *Please keep wanting to know more things.*) In drawing attention to suffering, interpretation becomes the unnecessary villain, perpetuating the pernicious premise that cancer results from emotional repression (Vanhoutte, 2002, pp. 394–395; Sontag, 1978). It's as though the Fortress of Biomedicine's claim to exclusive epistemic privilege—putting up walls around its perimeter—has tainted the very notion of knowledge and interpretation, and so they must be unilaterally condemned alongside the depraved physician-scientists. Instead

of fully empowering the "patient" protagonist as a *bearer* of knowledge with the right to interpret, the play becomes a tragedy, as Bearing's cancer is punishment for her over-*bearing* hubris, which mirrors her physicians' arrogance (Vanhoutte, 2002; Irvine & Spencer, 2017a, pp. 65–64). What a bear this all is! The distinguished scholar will not be a co-author of the research paper about her nor of anything at all, any more; no longer a writer nor reader, she foresees that after her death she will be reduced to the patient-text of the journal article about her ovarian cancer, "just the white piece of paper that bears the little black marks," as she puts it (Edson, 1999, p. 53).

While punishing Bearing for wanting to know more things is quite troublesome, the play's explicit parallel between literary and medical reading highlights the fact that in both domains, "narrative competence" isn't enough. Knowledge isn't the problem, though; it's knowledge at the unnecessary expense of compassion. As Bearing points out, "The young doctor [Jason], like the senior scholar [Vivian], prefers research to humanity"—and as death approaches, she ruefully recollects her own lack of sympathy toward her students, as when she didn't grant a paper extension to a student whose grandmother had just died (Edson, pp. 58, 63). Similarly, limiting the purview of clinical reading to pathophysiology ignores the lived experience of illness and can cause very real harm.[5] Even when the scope is broadened to invite a more nuanced and expansive reading of the patient's narrative, it remains insufficient. Indeed, what the textual metaphor reveals is that an instrumental methodic emphasis on the doctor-as-reader *must* be guided by ethics, *must* be put at the service of humanity and compassion, and *must* evolve into a more reciprocal hermeneutical process wherein the ill person is equally a reader. Crucially, in *W;t*—as in narrative medicine—the textual metaphor invites such ethical consideration. Thus despite the play's own tragic flaws (helpfully illuminated by hermeneutics), its thematic emphasis on reading and interpretation and illumination of the question of who is inhabiting which roles is an important development. For while the doctors don't hear Vivian's narration of the hospital drama, we do; as audience members, we are prompted to consider our own roles as readers and interpreters of texts of all sorts.

Fortunately humanity and hermeneutics are not at all antithetical—quite precisely the opposite, in fact—as writer/critic Anatole Broyard demonstrates in an essay about his own illness, first published in *The New York Times Magazine* as "Doctor Talk to Me" in 1990 and then in the posthumous *Intoxicated by My Illness* as "The Patient Examines the Doctor"

in 1993. Ostensibly recounting the story of his experience with prostate cancer, the essay also skillfully and subversively plays with the reader/writer roles vis-à-vis the doctor–patient relationship, claiming hermeneutical capacities for both as a shared privilege of being human. Broyard begins with the classic doctor-as-reader formulation: "I want [a doctor] who is a close reader of illness and a good critic of medicine. I cling to my belief in criticism, which is the chief discipline of my own life." Here reading is understood to be intertwined with criticism—which is to say, again, that narrative invites hermeneutics, for what else is criticism but interpretation? Indeed, once the doctor/reader analogy is established, Broyard reverses the roles, with the *doctor* as text: "I subjected the doctor to a . . . semiotic scrutiny," he explains, elaborating that "while he inevitably feels superior to me because he is the doctor and I am the patient, I'd like him to know that I feel superior to him, too, that he is my patient also and I have my diagnosis of him. There should be a place where our respective superiorities could meet and frolic together" (1993a, pp. 40, 35, 45).

As the roles are inverted, moreover, both patient and doctor are understood to be critics and writers. For his part, currently playing the role of patient, Broyard explains that "once we had a narrative of heaven and hell, but now we make our own narratives. I'm making my own narrative here and now." And he would also like to recuperate such possibilities for the doctor as well: "I think that the doctor can keep his technical posture and still move into the human arena. The doctor can use his science as a kind of poetic vocabulary instead of using it as a piece of machinery, so that his jargon can become the jargon of a kind of poetry." Finally, patient and doctor, shifting roles, can engage as critic-writers together: "Whether he wants to be or not, the doctor is a storyteller, and he can turn our lives into good or bad stories, regardless of the diagnosis. If my doctor would allow me, I would be glad to help him here, to take him on as my patient" (1993a, pp. 42, 44, 53).

Having begun with the doctor-as-reader, we find that this figure invites its own subversion, as reading invites criticism, which is to say hermeneutics—and being a writer/critic is a way of experiencing oneself as human. Thus the textual model here becomes a Trojan horse-Book, pulling hermeneutics from within itself as a means to restore humanity and reciprocity to *both* doctor and patient, deconstructing the walls of the Fortress of biomedicine without renouncing (nay, in fact munching upon!) the formidable fruits of its technical knowledge. If in Edson's *W;t* Bearing ultimately loses her words and trades them in for kindness, shucking her clothes to become, at her

death, “naked and beautiful, reaching for the light” (1999, p. 85), Broyard holds onto his words and interpretive powers—alongside kindness—as an index (for him) of being alive. In “Toward a Literature of Illness” he cites Winnicott’s unfinished autobiography, which includes the line, “I was alive when I died.” “Though he never finished his book,” Broyard writes, “he gave the best reason in the world for writing one, and that’s why I want to write mine—to make sure I’ll be alive when I die” (1993b, p. 30). As indeed he was.

Questioning the Nature of Reading and of the Text

As these creative works demonstrate, the textual metaphor productively invites reconsideration and subversion of the roles of reader/writer/text. In addition, it provokes interrogation of the very nature of reading and of the text itself. If training medical students in narrative competence creates a double effect of offering them the opportunity to share their affective experiences in the parallel chart, admitting the Book into the Fortress of Biomedicine as a clinical methodology has the double effect of introducing a contemporary narrative hermeneutical approach.

This is particularly useful to medicine as a tool of epistemic self-reflection, because the evolution of hermeneutics offers an instructive example to the Fortress. For while contemporary hermeneutics is quite distinct from its historical roots, its origins lie in biblical exegesis. As Terry Eagleton describes, in the scriptural tradition “the primordial Word is refracted amongst his various texts, which thus demand scrupulous decodement for the life-giving discourse of their Author to sound through. . . . In a double hermeneutic, historical significations must first be referred to the privileged signs of scripture, which must then be themselves disencumbered of their polyvalence to reveal a unitary Truth” (1981, p. 14). And medicine certainly reckons with its own conception of a unitary Truth—a divine adjacency, if you will. As Voltaire proclaimed: “Men who are occupied in the restoration of health to other men, by the joint exertion of skill and humanity, are above all the great of the earth. They even partake of divinity, since to preserve and renew is almost as noble as to create”[6] (1901, pp. 197–198). Moreover, by the late 19th century diagnosis becomes, as Lennard Davis suggests, a form of gnosis “implying the certainty of religious knowledge . . . opposed to the doubtful,” prompting us to see “the physician as displacing the divine as the source for certain knowledge” (2014, p. 85). The epistemic framework of contemporary

medical rhetoric and practice is one in which the role of the clinical narrator is elided by the agentless passive voice (*the procedure was attempted*)—for the narrator is but a vessel for Divine sight, deploying the omniscient Foucauldian "loquacious gaze with which the doctor observes the poisonous heart of things" (Foucault, 1994, pp. xi–xii). Moreover, medical texts must omit or bracket the patient's lived experience in order to be *disencumbered of their polyvalence* and to guard the methodic preserve of the Fortress.

The pragmatic/methodic emphasis on exercising "narrative competence" as a clinical tool carries a strain of this older form of hermeneutics, one grounded in biblical exegesis—extracting the meaning encoded in the patient-text and restoring it to a unitary Truth—in order to make itself useful and explicable to the priests of the temple/Fortress. Yet, again, it also bears forth the contemporary understanding of hermeneutics, exposing the act of interpretation, its contingency and situatedness, its inescapable multiplicity. This is what reading, writing, and interpretation does.[7] The tension regarding the form of interpretation in narrative medicine thus recapitulates the tension in hermeneutics—that it was historically understood as a search for "a hidden 'ultimate meaning' that waits to be discovered in the depths of the object of interpretation," as Rita Felski describes (2015, pp. 32–33). In recuperating hermeneutics, however, Felski argues that it is not necessary to limit interpretation to such a conception:

> While the retrieval of hidden truths is one kind of hermeneutics, not all hermeneutics require a belief in depth or foundations. . . . [Ricoeur] declares that his hermeneutic philosophy addresses "the existence of an opaque subjectivity that expresses itself through the detour of countless mediations, signs, symbols, texts and human praxis itself." Interpretation, in this view, is a matter of conflict and disagreement, of mediation and translation; it does not require a "transcendental subject" or a stance of heroic mastery. (2015, p. 34)

This aligns with Meretoja's own reimagining of narrative hermeneutics as a practice "animated by the conviction that we should move beyond linking interpretation to the idea of unveiling deep meanings; we should see interpretation as an endless activity of (re)orientation, engagement, and sense-making, which is thoroughly worldly, both in the sense of being embedded in a social and historical world and in the sense of participating in performatively constituting that world" (2017, p. 10). And this is precisely the form of

hermeneutics emerging out of the belly of narrative medicine's Book once it penetrates the Fortress of biomedicine.

The utility of preserving the legacy of the methodic approach toward creative works—any notion that there is a singular meaning to be uncovered, figuring the positivist medical gaze extracting the secrets from within the diseased body—is that it readily shows its own impossibility and insufficiency. For if, as Baron proposes, "the postulation of 'text' in clinical medicine creates an expectation of a source document, a foundational transcendent reality from which interpretations spring" (1990, p. 27), such a text *cannot* be located and fixed. Instead, the text—literary, human, or otherwise—resists mastery; the human being is *never* the sum of their pathophysiology, nor is their story ever singular, nor can it be fully grasped. This inexhaustibility is powerfully experienced in engaging with literature, visual art, and other forms of creative expression, as they both welcome and complicate attempts at reductive reading.

For example, as writer Donald Barthelme says of Rauschenberg's Monogram (the goat within a tire): "What is magical about the object is that it at once invites and resists interpretation. Its artistic worth is measurable by the degree to which it remains, after interpretation, vital—no interpretation or cardiopulmonary push-pull can exhaust or empty it" (1997, p. 20). Narrative interpretation as a clinical intervention will not "treat" the text with its methodic CPR; instead, the text challenges reading, challenges the reader, shows them to themselves. Rita Felski's description of Althusserian criticism also suggests the text-as-patient metaphor: "Just as the hysterical patient is racked by symptoms whose meanings and causes she cannot comprehend, so the literary text is riven by absences and fissures that call up social contradictions it cannot consciously address. . . . [its] symptomatic evasions and displacements, once diagnosed and traced back to their origins, afford insight into the forces that spawned them" (2008, p. 80; Spencer, 2021a, p. 299). But such a "symptomatic" reading characteristic of Althusserian criticism is superseded by a more hermeneutical understanding that such meaning *cannot* be extracted from the text like a diagnosis from the body, as reading is a dialogical co-creation. Here the evolving understanding of the way literary texts work can be expressed in clinical metaphor, and informs the textual metaphor as it enters healthcare. For the diagnostic gaze, turned toward the patient-text, finds that any text is situated within a much broader framework, and interpretation does not stop at the body's edge, so to speak, but applies equally to the reader. Rather than *unveiling deep meanings* through CPR or

diagnosis, the method leads us to hermeneutics—to an awareness of the interpretive process.

This is a dialogic model of reading that invites uncertainty. And this is the stance of contemporary narrative medicine, as in Charon's description of the exhilaratingly bewildering process of reading David Foster Wallace's *Infinite Jest* with a group of medical students:

> In between dissecting their anatomy cadavers and learning of brutal diseases that take lives, they'd read Wallace's edgy leave-nothing-left-unseen PET scan of ordinary life exposing the surreality, the madness, the faceted fractaled epiphanic that can sometimes be fleetingly seen amid the cynical, the fantastic, and the habitual. . . . Hermeneutic, their efforts with this novel became a model for a form of dynamic and creative thought that registers detail while constructing pattern, that tolerates chaos, that is moved by proportion and balance and contrast, that is led to remember things, that colors itself with emotion, and that appreciates the presence of the thinker in the thought. (2017a, p. 180)

As Charon explains, reading reveals not a unitary truth, but the polyvalent uncertainty of interpretation, emotion, and of life itself. The text—X-Ray, PET scan, novel, patient's account of illness—is not simply a signifier denoting its worldly signified, its meaning to be extracted by means of a routinized drill. Instead, it shows itself as an interpretation, a profoundly dynamic process introducing hermeneutics into the walls of the clinical space. It illustrates Gadamer's point that "the human sciences are connected to modes of experience that lie outside science: with the experiences of philosophy, of art, and of history itself. These are all modes of experience in which a truth is communicated that cannot be verified by the methodological means proper to science" (2004, p. xxi).

Moreover, just as literature has critiqued the premise of realism through myriad means—from metafiction to the self-awareness characteristic of the contemporary novel (certainly including DFW's oeuvre)—the textual metaphor also reveals biomedicine's reading and interpretation to itself, critiquing its realist premise (Spencer, 2021a, p. 304). Which is not to say that the Fortress's biomedical claims don't reflect the material world at all (let's hope, for all of our sakes, that they do) but they are indeed situated and changeable, and they co-exist with many other facets of human experience. When narrative medicine workshop participants search for meaning in a literary text,

they grapple with the question of where such meaning is situated: Intrinsic to the text or the author's intention, and/or constructed by readers? What does it *really* mean? *Is* there a singular meaning to be disclosed, or does the individual and collective interpretive process show itself as powerfully constitutive of the text's evolving and multiple meanings? And, once introduced, hermeneutics prompts questioning of biomedicine's exclusively positivist premise. Does the meaning of an attention deficit hyperactivity disorder (ADHD) diagnosis, for example, simply refer to a material referent such as a neurochemical state? Or is it also constructed by our labile diagnostic categories and mediated by social context (Spencer, 2021a, p. 301)? Is the meaning as variable as are all the human beings who carry the diagnosis and the lives they lead? Reader, how could it *not* be?

If reading invites interpretation and subversion of readerly roles—and of our understanding of the text itself—narrative medicine also offers another means of unsettling fixed interpretation in the act of writing. When narrative medicine workshop participants, for example, are encouraged to write to a prompt and then share what they have written, it evinces the role of language. As Barthelme describes: "The combinatorial agility of words, the exponential generation of meaning once they're allowed to go to bed together, allows the writer to surprise himself, makes art possible, reveals how much of Being we haven't yet encountered." Writing enacts its own constructedness, demonstrating that "art is always a meditation upon external reality rather than a representation of external reality or a jackleg attempt to 'be' external reality" (1997, pp. 21, 23). Once performed in relation to a literary text or personal reflection, this awareness seeps into the air of the Fortress—again, challenging biomedicine's exclusive claim to realism, which is to say neutral objectivity. For in writing one is crafting a narrative, whether it is a prose poem or a clinic note. When narrative hermeneutics enters the gates, it helps to illuminate clinical texts as such, and to invite interpretation.

Questioning Diagnostic Narratives: Metagnosis

In this spirit of illuminating the clinical text as one among many, I take a hermeneutical approach to diagnosis in my work. I adapt the tools of narrative medicine, elaborating them not as a clinical methodology per se but rather as means of research combining interdisciplinarity, narrative attentiveness, and the construction of a Barthesian *writerly text* which resists

closure, unsettling the reader and "bring[ing] to a crisis his relation with language" (Barthes, 1998, p. 14; Spencer, 2021a). Such a hermeneutical stance challenges "structuralist, empiricist, and positivist philosophies of science and knowledge . . . by centering on our capacities of interpretive understanding, interacting, and meaning construction," as Brockmeier and Meretoja describe (2014, p. 4). In *Metagnosis: Revelatory Narratives of Health and Identity*, I utilize this approach to explore the phenomenon of a belated diagnosis—an adult revelation of a long-standing yet undetected medical "condition," previously unknown even to the person who has it (2021a). This can happen when the condition was simply never detected (as was the case with my long-standing visual field "defect") and/or because the diagnostic boundaries have shifted, as frequently occurs with ADHD or autism spectrum "disorders."

Because such an experience so often prompts an abrupt change in one's conception of normalcy, disease, disability, identity etc., I term it *metagnosis*, for *changed-knowledge*. It invites hermeneutics, illuminating the pathological reading as but one interpretation among many. Indeed, an individual's lived experience frequently challenges the status of the diagnosis as an exclusively authoritative text, particularly when it is offered retrospectively. Analogously, a metagnostic revelation of biological parentage might offer the sudden appearance of a genetically "real" father alongside the "real" father who raised the child—the person who, as memoirist Dani Shapiro describes her own father, "loved me into being"—productively illuminating changeable interpretations of what constitutes the real (Spencer, 2021a, p. 315; Shapiro, 2019, p. 249). Metagnostic medical revelations are also unsettling because they often illuminate shifting diagnostic parameters—as when Asperger syndrome appeared in the *Diagnostic and Statistical Manual of Mental Disorders* and then disappeared thirteen years later—challenging diagnosis as an exclusive mimetic representation of reality. Instead, the interpretive nature of these different readings is exposed, and they are put into play with one another.

The "meta" in metagnosis suggests *change*, and here meaning is ever-changing. It is not a biblical hermeneutics of uncovering a fixed point of divine meaning, but an experience of Aristotelian *anagnorisis*, or recognition, which has evolved from a revelation of a static originary truth to an understanding that, as Terence Cave describes, "the story . . . may always be reopened." Indeed, "the fall of recognition from grace originates in a historical event, the demise of the 'sacred masterplot,' the decay of belief in a

true supernatural genesis and revelation" (1988, pp. 24, 218; Spencer, 2021a, p. 184). In place of this belief, we can acknowledge that the process of interpretation is generative and ongoing, and focus on the real-world *effects* of various narratives. We can welcome what Meretoja describes as a hermeneutic narrative ethics, in which narratives are understood to "both expand and diminish our sense of the possible," and narrative practices are evaluated as "oppressive, empowering, or both" (2018, p. 2). In *Metagnosis*, I share Meretoja's aim to "provide resources for analyzing the different dimensions of the ethical potential and dangers of storytelling" (2018, p. 2). To whit: How might a diagnostic narrative such as a belated label of autism be constraining, empowering, stigmatizing, and/or liberating for the particular individual in their specific lifeworld? How might that change over time?

Another way of framing this is to ask how we might understand diagnoses not as "naturalizing narratives, which hide their own mediating and interpretative role" but rather as "self-reflexive narratives, which openly present themselves as narratives, that is, as selective, perspectival interpretations that can always be contested and told otherwise," to adopt Meretoja's distinction. As she describes, naturalizing narratives are often "subsumptive," seeking "to subsume the particular under the general," while non-subsumptive reflexive narratives "destabilize such appropriative aspirations and display a non-subsumptive logic by foregrounding the temporal process of encountering the singularity of the narrated experiences" (2018, pp. 12–13). This distinction evinces the tension within narrative medicine between a more instrumental clinical methodology of deploying "narrative competence" and a process-oriented hermeneutics, with the utilitarian "naturalizing narrative" of doctor-as-reader-of-patient-text evolving toward a self-reflexive narrative, open to interpretation and uncertainty. It also empowers the individual faced with a metagnostic revelation to reject a subsumptive naturalizing diagnostic narrative (*you are autistic; that now defines you*) in favor of a self-reflexive narrative—to understand oneself as a person with autism who can explore different meanings and implications of the diagnosis specific to one's singular lived experience. This shift also emboldens us to flip the readerly roles, following the example of Bearing and Broyard, and become active readers, writers, and interpreters of the diagnosis as but one thread in the ever-changing textual fabric ("text" derived from the Latin *textus*, also meaning weaving) of our lives. This is narrative hermeneutics in practice.

While I examine these curious metagnostic revelations as a particular focal point, ultimately my claim as a narrative medicine

scholar-practitioner-activist is much broader: we must reject reductive biomedical narratives issued by the inhabitants of the Fortress. We must band together and take down the walls. We must claim hermeneutical agency and recognize that we are, all of us, readers and writers and interpreters, and we must remain open to the ways interpretation can change our understanding of ourselves and our world (Spencer, 2021a, p. 44; Brockmeier, 2015, p. 177). And if narrative medicine's textual metaphor helps us to better understand and take up this challenge, then it is doing good, useful, ongoing work.

Beyond the Book

The textual metaphor thus proves useful in advancing a hermeneutical understanding of the clinical encounter as well as diagnosis. Such narrative analysis can also help to address the use and abuse of stories in the context of public health, such as the COVID-19 pandemic.

For example, a 2018 RAND report describes an epidemic of "truth decay" in the United States, driven by polarization and "the blurring of the line between opinion and fact by creating opposing sides, each with its own narrative, worldview, and facts" (Kavanagh & Rich, 2018, pp. xiv–xv). Such truth decay purportedly produces cavities in the enamel, dentin, and pulp of our civic life, eroding trust in scientific data, such as that which concerns the safety and efficacy of vaccines. Here "narrative" is aligned with "anecdote," distinct from "evidence," which is understood to be generalizable (pp. 7, 11). Yet what this framing elides is that anecdote is a *form* of data, and data cannot be presented without a particular selection and context; in other words, as a narrative. Moreover, as Gadamer reminds us, applying a methodic search for scientific evidence to the entirety of human experience with a formal technique claims a false superiority. ("Evidence-based medicine" is precisely this type of false superiority, as it arrogates to itself the prerogative to determine which forms of evidence constitute evidence.) As a hermeneutical orientation toward clinical practice demonstrates, "truth decay" will not be forestalled by continuing to build up the walls of the Fortress, with data and evidence solely within its preserve. Instead, we must continue develop our narrative interpretive capacities in order to evaluate these truth-claims and their effects. Emphasizing the importance of narrative interpretation is not the cause of but rather our safe and effective prophylactic vaccination *against* nihilistic relativism. Flossing the gums of our interpretive canines can be

painful if we haven't done it in a while; however, if we want to avoid truth decay, it's a vitally important habit to maintain.

As we have seen, the textual metaphor prompts a generative working-through of the tension between method and hermeneutics in a variety of different contexts. It becomes what sociologist Sherry Turkle terms an "idea-object," which invites people "to think about the self in relation to the social world" (2022, p. 246)—in this case, to consider the individual's role and responsibilities in the healthcare space. It also encourages us to contemplate the ways in which it does *not* capture aspects of what happens in the clinical setting. For beyond the matter of who rightfully occupies the role of reader/writer and what kind of meanings inhere in a text and/or are constructed through interpretation, we might also find crucial aspects of healthcare that are perhaps not addressed by the textual metaphor, but illuminated nonetheless—provoking us to ask more *what about?* questions.

For example, what about presence? Recall Leder's claim that medicine has been led away "from the very real presence upon which it is founded: that of the living patient" (1990, p. 21). Speaking of living patients, once upon a time I navigated a medical odyssey involving multiple eye surgeries, serial medical errors, and a dramatic metagnostic neurophthalmic plot twist (Spencer, 2013, 2015, 2021a). There was much complex interpretation involved at every stage. But one of the most significant moments of this journey for me had not much to do with interpretation. It occurred while I was corresponding with my surgeon during a difficult time (he was trying to correct the previous surgeon's errors, and we'd experienced a setback), and he revealed that he'd just been to the ophthalmologist himself. When I asked him how it went, he noted that the dilating drops were really annoying, and then added, "I am sorry that you have to have had so much done to your eyes." This was an act of care, with one human humbly offering presence to another, reflecting what Broyard identified as the existential responsibilities of the physician: "Every patient invites the doctor to combine the role of the priest, the philosopher, the poet, the lover. . . . he himself, his presence, and his will to reach the patient are the assurance the sick man needs" (1993, pp. 54–55). If the textual metaphor does not describe such presence as a fundamental aspect of healthcare, perhaps that very limitation helps to elucidate and elevate the importance of presence, and to ask what role it should play.

Which is to say that if the roles of *reader* and *writer* or the nature of the *text* do not map precisely onto the clinical space, conceivably that is in itself helpful to us. "Perhaps," as Carter suggests, "it is the points of most obvious difference

that lead to the most interesting speculations, as literature and medicine serve as poles for a dialectic, illuminating each other" (1986, pp. 148–149). Indeed, the textual metaphor enacts the very "wrongness" of metaphor itself, which "asserts of one thing that it is something else," evincing "the act of symbolization, [which] is itself the instrument of knowing," as Walker Percy describes (1958, pp. 81, 98). This, too, helps to challenge the Fortress's realist premise, showing it that it is indeed symbolizing, representing the world in a particular way, and summoning us to conceive of alternatives. For we are active participants in this dialectical process of understanding—questioning genuinely and openly, as Gadamer would have it.

Once the Book breaches the gates, hermeneutics invites these queries. If the roles of reader/text prove to be so slippery, for example, then what of the corresponding distinctions divided by the walls of the Fortress, such as doctor/patient, objective/subjective, subject/object, skill/emotion, divine/human, mind/body? The hermeneutical stance of narrative medicine, sprung from the belly of the Book, beckons us to interrogate these distinctions and to imagine that we may deconstruct the wall dividing the terms. For if literature invites us to "imagine alternative realities," as Barthelme describes, it also gives us the tools to transform our reality, as "the aim of meditating about the world is finally to change the world. It is this meliorative aspect of literature that provides its ethical dimension" (1997, p. 24). Ultimately this hopefulness is what the Book at the gates offers to medicine, which needs all the meliorative help it can get. It may just help us, finally, to change the world.

Notes

1. The exclusive emphasis on biomedicine in US medical education was articulated in the influential 1910 Flexner Report, which omits ethics, social responsibility, and humanism from the prescribed course of study (Flexner, 1910).
2. See Arthur Frank on illness typologies (1997).
3. For an important Levinasian framing of this role for literature vis-à-vis clinical education, see philosopher and narrative medicine scholar Craig Irvine's "The Other Side of Silence: Levinas, Medicine, and Literature" (2005).
4. For more on the hermeneutical strains of narrative medicine, see Irvine and Spencer (2017b), Irvine and Charon (2017).
5. As Eric Cassel describes: "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. . . . Physicians' failure to understand the nature

of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself" (1982, p. 639).

6. What is not typically included in Voltaire's quote is his assertion, just prior, that "out of every hundred physicians, ninety-eight are charlatans" (1901, p. 197).
7. For example, Walter Benjamin's study of puritanism in the 18th-century novel as founded upon the living Word of God resulted in, as Eagleton describes, its own self-dissolution: "An idealism of the literary sign fatally inverts itself into a mechanical materialism of the subject: Defoe's 'degree zero' writing clears a space for that subject's expressivity, only to find that space then crammed with material *signata* which threaten to engulf and confiscate subjectivity itself" (1981, p. 15).

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