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Introduction

THE PATIENT OCCUPIES A LIMINAL, UNSTABLE POSITION, PRECARIOUSLY situated between home and hospital, work and bed, life and death. Although the patient is attended by doctors, nurses, family, and friends, her condition—particularly if it is chronic—threatens to sever her connections with the world as she has known it and to exile her into that fundamental solitude owned by the sick and suffering. Such existential dimensions of sickness have intensified during the twentieth and twenty-first centuries in a paradoxical way: benefiting from new diagnostic and therapeutic modalities that would have been unimaginable a few decades ago, patients now live longer than ever. Consequently, in many cases, they also suffer longer than ever. Nor is this suffering a distant abstraction to be discussed solely in the third person; we who read the essays that follow surely come to this topic with personal experience of one who has been—or who will inevitably become—a patient.

It is this inevitability that, in the fall of 2006, brought together an international cadre of scholars on the campus of Bucknell University to explore multiple dimensions of patienthood: autobiographical, sociological, historical, and artistic. From countries including India, Ireland, France, and Canada, forty delegates joined forces to raise critical awareness of what it means to be ill, not only on the intimate level of lived experience, but also in broader cultural contexts in which—and by which—illness is defined and shaped. The ten essays that follow reflect the variety of perspectives that emerged during the symposium and are intended for students and professionals in both the humanities and medical sciences. We have therefore asked contributors to minimize disciplinary jargon in order to accommodate an interdisciplinary readership without compromising the substance or complexity of the material.

A common thread throughout these writings is the suffering of patients and how we as individuals and societies understand that suffering, sometimes inadvertently perpetuating it out of ignorance, and usually attempting to assuage it through mindful attention to it. In order to get to the heart of what many of these essays address, it is important to remind ourselves of the commonly recognized distinction between disease, as the pathological alteration of structure and function at the cellular and subcellular levels of the body, and illness, or the person's response to that alteration: the body becomes diseased; the person becomes ill. It is illness that causes the greatest suffering, because a person's experience of illness, if the illness is severe enough, entirely alters one's perception of oneself and one's future.

In his classic book entitled *The Nature of Suffering and the Goals of Medicine,* internist and bioethicist Eric Cassell defines suffering as "the state of severe distress associated with events that threaten the intactness of the person,"[1] and he persuasively illustrates how suffering occurs when one's personhood is threatened. By personhood, Cassell means the entirety of who we are: our personalities and character, our past and our memories of it, our life experiences, our family and cultural background, our various roles—indeed, the whole intricate "web of relationships" with self, family, and society.[2] Illustrating Cassell's point, four of the authors below offer intimate accounts of how their own and their family members' personhood has been threatened by illness.

In "Scheherazade Syndrome: Illness and Storytelling," Kristin A. Lindgren reveals several ways in which suffering both encompasses and extends beyond the physical body. Wellness and illness are, of course, not binaries; in various shades of gray, "good health" and "poor health" exist along a continuum, and sometimes keen existential crises arise when people differ on what constitutes a legitimate illness. Such is Lindgren's experience with chronic fatigue syndrome (CFS), a condition notoriously difficult to diagnose and even more difficult to treat effectively. Combining journal entries and retrospective analysis, she recounts the frightening onset of symptoms two years after the birth of her son—symptoms of an illness whose cause eludes her doctors. Sociologist Kathy Charmaz discusses the ramifications of elusive diagnoses like Lindgren's and concludes that patients often feel as though their physicians consider them—or have portrayed them to others—as "feigning illness, either by magnifying insignificant symptoms or by psychologically inducing physical distress."[3] Over time, when family and friends begin to doubt the validity of a patient's symptoms, patients "even begin to distrust their own bodily sensations,"[4] which can lead them to doubt their powers of perception and sometimes even their sanity. While Lindgren does not dwell on such doubts, she nevertheless provides unique insight into how suffering is often intensely private, silent—how it happens interstitially, between medical appointments, procedures, treatments. Lindgren capitalizes on her expertise as a literature professor, examining the process of telling and revising her story as the condition worsens, and considering the implications of the differences in her own story of the illness and the stories that doctors construct around it. Mindful that putting something into words not only describes a reality but often actually creates it, Lindgren uses her aptitude with words to envision a reality in which she can exist more meaningfully—at least until the nature of her condition requires a new version of the story: "[J]ust as I think I am learning to live creatively within the confines of a sonnet, the rules change. Suddenly it is a villanelle."

In passages about her son and how the two of them create novel approaches to deal with her failing health, Lindgren underscores the fact that suffering is never confined to an individual. It bleeds into families, but, despite its enormity, the familial dimension of suffering is often overlooked. Focusing on the patient and his needs, the caregiver must frequently ignore her own physical and emotional challenges for the sake of time and energy; her full attention must go toward caring for her loved one. Such is what we witness in Carol Schilling's piece about her son's skiing accident that left him wheelchair-bound. In "Feathers Rose from the Floor as I Walked through the Doors of the ER," Schilling offers an intimate account of the minutes after learning of her son's accident and shows with piercing clarity how fully and suddenly family members' lives can change. Schilling's son's accident results in what Charmaz defines as an illness of "intrusion," in which the effects of illness do not simply disrupt life temporarily but continue indefinitely, forcing patients and their families to accommodate to it.[5] Schilling and her family are, in fact, resourceful in accommodating illness, and although her son is not restored to complete health and mobility, the family adapts in creative and supportive ways. Throughout this process, the Schillings exemplify another key Charmazian concept in that they "reconcile" themselves to what the accident brings: they endure the illness but reject the stereotypes others cast upon patients with such conditions.[6] In this way, they view the liminal space of illness as one of hope and resilience in which even permanent disability does not define the patient. Ultimately Schilling's narrative is one of transcendence.

Not so with Gayle Whittier's essay, "Wounded Imagination: Prosthesis, and 'Recovered' Art," in which she, in her own words, "shifts antiphonally between more distanced commentary and first-person witness." Striving to find a meaningful narrative structure for her daughter's disability, Whittier examines her own story alongside those of three authors who grapple with similar issues: Marie Killilea's memoirs *Karen* and *With Love from Karen,* Kenzaburo Oe's autobiographical novel *A Personal Matter,* and Giuseppe Pontiggia's novel *Born Twice.* While assembling a community in which to situate herself, Whittier is finally left with what medical sociologist Arthur Frank, in his book *The Wounded Storyteller,* defines as a "chaos narrative,"[7] one without plot or tidy resolution. Whittier's essay enables us to understand the effect of chaos narratives as "the repetition of 'and then' events [. . . that] grind down time and space until the witness loses any orientation and feels trapped in the sufferer's maze. The chaos narrative offers no guideposts, no numbered stages that lead to acceptance. In chaos narratives, nothing leads anywhere. . . ."[8] Precisely because they withhold the consolations of closure, chaos narratives yield crucial insight into the fundamental isolation and fear that come with a devastating diagnosis.

Poet Tess Gallagher's essay "Beyond Forgetting," on caring for her mother until the latter's death from Alzheimer's, conveys the hope and potential to wrest the chaos of that disease into some meaningful, if not fully transformative, experience. Gallagher delivered a keynote address at the symposium, interspersing original poems with an account of her mother's decline and thus signaling the therapeutic possibilities inherent in lyrical meditations. Far from the bleak and hopeless stories of Alzheimer's that dominate contemporary media, Gallagher's exploration of the disease peels away layers of the superfluous to reveal creative potential in reshaping expectations for those who are ill and for their caregivers.

Autobiographical stories of illness such as these provide powerful—yet necessarily circumscribed—insights into patienthood. On the most basic level, the immediacy of a patient's voice and her unique way of conveying lived experience make her story memorable for lay readers who might thereby be prompted to think about issues they had not yet considered vis-à-vis their own illness. This dynamic narrative triad of writer-text-reader also empowers patient-readers by providing them with germane questions to discuss with their physicians and therefore ultimately serves to enhance their overall health in concrete, pragmatic ways.

If the content of narratives is useful, so too is the narrative form itself since narrative enables people to make sense of information economically and effectively. As educational sociologist Parker Palmer explains in his discussion of patient-centered medical education:

> the human brain works best with information presented not in the form of isolated data bits but in patterns of meaningful connection, in a community of data, as it were. Patterning is what happens when students learn their medical facts through a patient's story, for that story . . . connects various facts about the patient with each other in a pattern of correlation and interpretation and explanation, and it connects the student with the patient in a pattern of human meaning. [Learning in this way offers students] a chance to look at reality through the eyes of others, instead of forcing them to process everything through their own limited vision.[9]

Palmer's observation indicates why medical humanities programs utilize patient illness narratives, or pathographies, as key components of their curricula for medical students. Indeed, the raison d'être of medical humanities itself is to provide the kind of person-centered perspective inherent in patient narratives, the "kinds of knowledge that cannot be reduced to scientific or quantitative terms" and that therefore "reclaim the personal, even spiritual, aspects of illness."[10] Reading patient narratives—and indeed literature in general—fosters professionalism in other ways as well. Based on her work with patients and texts, physician and literary scholar Rita Charon pioneered the concept of "narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others." Narrative competence is crucial to the "effective practice of medicine" on many levels: "physicians can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care."[11]

As Charon suggests, scholars in disciplines outside medicine also benefit from first-person patient perspectives by considering the more abstract issues raised by such narratives. Any philosophical discussion of theodicy, for example, is surely illuminated by a discussion of illness, whether that of the Old Testament Job or a contemporary poet. Autobiographical accounts of illness from patients of different cultures serve as excellent bases for anthropologists who note the unique role of various kinds of illness in a given culture; this fieldwork can, in turn, have a dramatic impact on the health-care practices within that culture and activist efforts from outside the culture on the citizens' behalf.

Despite their obvious merits, first-person accounts of patienthood also present challenges to a comprehensive understanding of what it means to be a patient. Understandably, a patient's position *as* patient necessarily delimits his or her comprehension of larger social or medical contexts. When suffering is intense and protracted, broader dimensions of patienthood—like health-care policy and the doctor-patient relationship, for instance—can become distorted through the lens of a single patient's perspective. And given the subjectivity of a patient's story, he or she can consciously or unconsciously relate inaccuracies through the details he chooses to recount and those he chooses to omit from his story. Consider the implications of professor-celebrity Randy Pausch's autobiographical account of his struggle with pancreatic cancer. Intending to find meaning in his illness and to make the best of his situation, he delivered an inspirational “last lecture” to his students at Carnegie Mellon University that later led to his best-selling book of that title. As scholar Lisa Roney illustrates, such narratives of transcendence can inadvertently burden the very people they hope to encourage. Very few patients are lionized as Pausch was during his final months with cancer, and many patients of lesser socioeconomic status could not even afford the basic—much less the best—medical attention indicated for a similarly dire condition. Such disparities raise the issue of ethical responsibility in telling one’s story.[12]

Considering questions like these extends the work of medical humanities beyond first-person perspectives. Accordingly, other contributors to this collection take a wider view of patienthood, examining it through the lens of history, politics, or culture—“contact zones,” as cultural studies scholar Mary Pratt calls them, “where cultures meet, clash, and grapple with each other, often in contexts of highly asymmetrical relations of power.”[13] Such is the case in “A Patient/Hospital Relationship in 1863–1865: Mainstream Doctors and Navajo Patients in the Bosque Redondo Camp.” Here, Susanne Berthier-Foglar draws attention to an instance of Native American relocation to an eastern New Mexico camp. While the white military physicians in charge of health care there might have been expected to assume a colonialist posture of paternalism, they were instead “open to Indian knowledge” and attempted to incorporate tribal values into the scientific (such as it was) medicine of the time. Berthier-Foglar concludes that the Native American beliefs and practices observed during this captivity altered contemporary health care for the better. Such studies as Berthier-Foglar’s balance the hypercorrective revisionist view of history that all too often reveals only the dark side of those in power without giving due credit to those who act with integrity, professionalism, and human decency.

Complementing Berthier-Foglar’s examination of Native American culture during the Civil War period in America are John Rickard’s analysis of the politicization of Irish women’s bodies and Amy McCready’s scrutiny of the medicalization of sexuality in Sweden at the turn of the twentieth century. These essays underscore the ways in which bodies are often contested sites of power—especially when these bodies are female. Rickard's essay on "The Irish Patient" presents a lucid distillation of complex national gender politics, which he draws into focus through the lens of two contemporary Irish women poets, Eavan Boland and Nuala Ní Dhomhnaill. Preferring more general images of illness and trauma to overtly medicalized bodies, Boland and Ní Dhomhnaill argue how political control operates vis-à-vis the actual human body—in terms of both control *of* the body and control *through* the body. Rickard's analysis of anorexia and scarring in these Irish poems offers an illuminating context in which to view various corporeal, social, and political manifestations of, among other things, body dysmorphic disorder in America, including eating disorders and acts of self-mutilation like "cutting." The issues foregrounded here point to the significant fact that patienthood is not merely a personal condition; it is often culturally enacted and perpetrated, inscribing pathology on a collective body.

Amy R. McCready's "Critical Cases: The Malleability of Health and Justice" explores the peculiar way sexuality is medicalized in a 1905 Swedish novel entitled *Doctor Glas.* McCready's opening synopsis extends as compelling an invitation into the labyrinths of a novel as one could hope for: "A woman who describes herself as 'perfectly well' asks a doctor to diagnose her as ill so that she can avoid sex with her husband in order to engage in relations exclusively with her lover. The doctor professes a problem with her health, and when her 'illness' proves insignificant relative to her husband's claims of marital duty, the doctor proclaims that the husband must refrain [from intercourse] for the sake of his health." McCready's essay raises important considerations not only about what it means to be ill—again, whether illness exists and who determines its existence—but also about the ways in which illness can be manipulated for personal gain. This novel anticipates the work of medical sociologist Talcott Parsons in the 1950s on the "sick role" and the patient's attendant rights (e.g., her exemption from normal social roles) and obligations (e.g., the mandate that she seek competent medical help and comply with the medical professional). McCready teases out the ethical subtleties of a complex doctor-patient relationship, especially from the perspective of a physician who is morally flawed.

Lisa Diedrich's essay, "Lying and the Performance of Patienthood," serves as an excellent companion piece to McCready's, examining, as it does, the manipulation of truth in medical contexts, the nature of lies, and the ethics of lying about illness. Accepting as a given that patients lie to their doctors and that doctors lie to their patients, Diedrich shifts "away from a consideration of truth as a thing that can be determined once and for all, to a consideration of truth as a practice"—in short, "not what a lie is but what it does in narrative and history, socially and politically." Diedrich's deconstructive reading parses the phenomenon of lying in various facets of medical care, including general doctor-patient communication, diagnosis, and treatment. Probing these issues in James Frey's *A Million Little Pieces* and Lauren Slater's *Lying*, she argues that the "authority of illness narratives—both official medical narratives of disease and patients' counter-narratives about the experiences of illness—is illusory." Ultimately, Diedrich makes a fascinating case for how lying serves the health-care system.

Lying, in some form, often comes in the context of culturally prescribed sick roles (â la Parsons). In *At the Will of the Body*, Arthur Frank discusses the pressure society exerts on those who are ill to be "good patients" either by "passing" as normal or by "covering," downplaying the difficulties of being a patient. In the chapter entitled "The Cost of Appearances," Frank writes, "At home the ill person must appear to be engaged in normal family routines; in the hospital she should appear to be just resting. When the ill person can no longer conceal the effects of illness, she is expected to convince others that being ill isn't that bad."[14] A patient's refusal to adhere to his proper role often disrupts life on multiple levels. Such is the case in Alejandro Amenábar's 2004 film *The Sea Inside* and Brian Clark's 1979 play *Whose Life Is It Anyway?* When the protagonists, both quadriplegics, decide they want to end their lives despite being well cared for, families, the medical establishment, and even the legal system itself are embroiled in the conflict. Catalina Florescu's essay, "Ne Habeas Corpus," examines how these two pieces depict the objectification of the body, especially as it pertains to medical equipment/technology and sedation, and the ways in which both patients' "visceral semantics, while in pain, deny[ ] this impersonal vision of a body qua object [and seek] to repossess its (temporarily) lost subjectivity." Grounded in contemporary theory and referencing pertinent and persistent mythological paradigms, Florescu's essay provides fresh perspectives on what it means to possess autonomy as she asks us "to reflect upon those instances when the body, although still *de facto* personal, cannot participate actively in life."

The protagonists whose biopsychosocial quandaries Florescu examines evoke in the viewer not only intellectual curiosity but also empathy. It is precisely this kind of identification of audience with character that Tara McGann examines in her essay "Intimations of Mortality: George Eliot's 'Janet's Repentance' and Narrative Ethics." Using the last of the three *Scenes of Clerical Life* by George Eliot as her focal text, McGann investigates "the disposition towards suffering that the text models and invites the reader to assume." As McGann notes, this essay "makes problematic the category of the patient" in that it considers "how the reader of [Eliot's] novella recognizes herself as an embodied reader subject to the pain and suffering" all people understand. Exploring the nexus of Eliot's novella, Arthur Frank's "remission society,"[15] and Rita Charon's model of "narrative medicine," McGann delineates a helpful construct of "narrative ethics," a concept that informs literary studies and medical humanities in equal measure.

In her landmark publication *Narrative Medicine: Honoring the Stories of Illness* (2006), Charon discusses how narratology—the study of how "stories are built, told, undergone, and understood"[16]—can illuminate the culture of medicine, ultimately enhancing communication in the clinical setting and fostering empathy for the patient. Each of the essays in this volume contributes to this important work in "medical narratology" by examining the ways in which our experience with stories—those we create as well as those we inherit—shapes our understanding of patienthood. Through their own stories and through analyses of stories constructed by others (both those presented as factual and those self-consciously imagined), these writers invite us to deconstruct and reconstruct meaningful assessments of patienthood.

Notes

1. Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine* (New York: Oxford University Press, 1991), 33.
2. Ibid., 37–40.
3. Kathy Charmaz, *Good Days, Bad Days: The Self in Chronic Illness and Time* (New Brunswick: Rutgers University Press, 1997), 24.
4. Ibid.
5. Ibid., 42.
6. Ibid., 47–48.
7. Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1997), 97–114.
8. Arthur W. Frank, "Dwelling in Grief," *Hastings Center Report* (January–February 2004): 46.
9. Parker Palmer, *The Courage to Teach* (San Francisco: Jossey-Bass, 1997), 127–28.
10. Susan M. Squier, "Beyond Nescience: The Intersectional Insights of Health Humanities," *Perspectives in Biology and Medicine* 50, no. 3 (Summer 2007): 335.
11. Rita Charon, "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," *Journal of the American Medical Association* 286, no. 15 (October 17, 2001): 1897.
12. Lisa Roney, "Dying Professors in Film and Television: How the Media Make Illness a Moral Issue," in *The Patient: Global Perspectives,* ed. Kimberly R. Myers (Oxford: Inter-Disciplinary Press, forthcoming, 2010).
13. Mary Pratt, "Arts of the Contact Zone," in *Negotiating Academic Literacies,* ed. V. Zamel and R. Spack, 173 (Mahwah, NJ: Lawrence Erlbaum Associates, 1989).
14. Arthur W. Frank, *At the Will of the Body: Reflections on Illness* (Boston: Mariner Books, 2002), 64–65.
15. Ibid., 138–42.
16. Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Oxford: Oxford University Press, 2006), 40.

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