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illness

AS NARRATIVE

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P.
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for my teachers

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Illness Narratives and the Challenge to Criticism

FROM THE WINTER OF 1918 until the spring of 1919, an influenza outbreak swept the globe, killing fifty to a hundred million people, as much as 5 percent of the world's population (Barry 397). Despite the flu's ferocity, for much of the twentieth century this pandemic nearly vanished from popular consciousness. Although more United States soldiers died from the flu than from combat during World War I, it has rarely been given a significant place in American histories of the war.¹ Even though, according to historian John M. Barry, it "killed more people in a year than the Black Death of the Middle Ages killed in a century" (5), the pandemic is virtually absent from American and British literature of its era. Mary McCarthy, whose parents both died of the virus when she was six years old, briefly mentions the flu at the beginning of *Memories of a Catholic Girlhood*. In the novel *Look Homeward, Angel*, Thomas Wolfe devotes one chapter to the death of the main character's brother, clearly a double for his own brother Benjamin, who died of the flu when Wolfe was in college. Influenza appears in the background of Willa Cather's war novel *One of Ours* and Wallace Stegner's *The Big Rock Candy Mountain*. Only one canonical work of fiction written in English places the epidemic at the center of the plot: Katherine Anne Porter's "Pale Horse, Pale Rider," a novella narrated in a feverish, dreamlike manner by a young woman who falls ill, almost dies, and revives just in time to hear the discordant noise of Armistice celebrations.² How to

bring the pandemic and the narrative form together? It is as if the project were unimaginable in the early twentieth century.

In stark contrast to the near silence that followed the 1918 pandemic, seventy years later a flood of texts appeared in response to the emergence of HIV/AIDS. In the United States, people with AIDS published a wide range of writing about their experiences of the disease, as did their doctors and caregivers. Journalists, playwrights, novelists, poets, memoirists, and diarists joined artists from other media in an effort to document the pandemic, create memorial art, and make meaning of suffering and loss on scales ranging from the individual to the global.³ A good portion of the published texts, from articles to book-length autobiographies, fall into the category the medical humanities defines as "illness narratives"—autobiographical accounts of illness spoken or written by patients. For the purposes of this study, in which I am concerned with how contemporary writers compose illness and how readers receive the accounts, I expand the works covered by the term to include fiction and blogs, as well as academic and popular commentary, and I broaden the range of authors to include family members, physicians, caregivers—even novelists. This broadened category makes ever more apparent the thunderous cacophony of voices about HIV/AIDS, and the volume of their stories about loss, sorrow, struggle, rage, and redemption or its absence.

What can account for *all this writing*? Why, in the 1980s and 1990s, did the quantity of writing about HIV/AIDS exceed that of any previous disease—not just flu, but tuberculosis, polio, cancer, and more?⁴ Much of the scholarship about these late-twentieth-century narratives tends to consider writing about HIV/AIDS in relative isolation, as if it were a product of a particular historical period when the virus threatened to decimate a generation of gay men.⁵ No doubt, AIDS required and continues to require a powerful literary response because it forms such a complex knot of personal, scientific, cultural, social, and political issues and because in the United States it has so deeply scarred the artistic community.⁶ But literature about HIV/AIDS did not develop in isolation, as I will explain in detail. It was preceded and accompanied by the emergence of a narrative form not available during the 1918 flu pandemic that has at its center personal accounts of illness and dying. As literary production about AIDS waned, however, the volume of autobiographical writing about illness and disability continued to grow, surpassing the rate of production of AIDS memoirs. Indeed, by the late twentieth century, illness and disability narratives were established as literary genres.

Since their ascendance, these narratives have shifted the boundaries of literary study. In the academy, for instance, accounts of illness have become central to the literary branch of medical humanism. Medical humanists who

teach literature in medical schools and centers have drawn attention to how narratives about suffering sustain individuals and communities. They observe how autobiographical illness narratives reclaim patients' voices from the biomedical narratives imposed upon them by modern medicine.⁷ They study, as well, how literary, popular, and medical narratives report and construct the experience of illness, from the personal level to the national.⁸ And they encourage medical practitioners to respond to the stories of suffering people with attention, respect, and understanding.

Such an approach to personal narrative is, however, out of step with mainstream literary criticism, which has not, by and large, recognized the significance of the work performed by such texts. The gap between the pragmatic work done by medical humanists in professional schools and the theoretical projects of scholars in the academy has long been evident but has not been examined and explained. *Illness as Narrative* makes the argument that one cannot fully understand writing about illness without also recognizing the split in critical attitudes toward these works. I contend, in fact, that literature about illness poses a special challenge to those current critical practices that are based in what Paul Ricoeur called the *hermeneutics of suspicion*. In *Freud and Philosophy*, Ricoeur writes that dual motives underlie literary interpretation: "[the] willingness to suspect, [and the] willingness to listen" (27). He sees suspicion and phenomenology as ideally counterbalancing each other in critical practice. In more recent decades, however, critics such as Eve Kosofsky Sedgwick, Bruno Latour, and Rita Felski have noted that the hermeneutics of suspicion has displaced what Ricoeur called listening and become "nearly synonymous with criticism itself" (Sedgwick, *Touching Feeling*, 124). Distrust of texts' errors, lies, and manipulations has become prescriptive, and the project of much contemporary criticism has become to anticipate and contain textual and theoretical problems in advance (Sedgwick, *Touching Feeling*, 130). For scholars trained in such habits of reading, the idea of trusting a narrative to provide access to the experience of another person indicates a naïve understanding of how such texts function. Before a contemporary critic begins to read an autobiography about cancer or pain, she knows that it has been constructed by medical discourse and political, economic, and cultural forces. She also knows that common readers are likely to misread it because they will assume they can try on the experience of the author and that they will therefore succumb to the myriad powers of dominant discourse. She is also likely to assume that the narrative itself is not as sophisticated or knowing as the theory she uses to interpret it. Such a suspicious critical position is not necessarily wrong, but it is incomplete. Literary critics' disdain for or disinterest in illness memoirs suggests, above all, that contemporary critics have become alienated from ordinary motives for reading and writing.

How might literary critics in the academy reclaim the “willingness to listen” that would enable them to attend more fully to the cultural work of writing about illness (Ricoeur 27)? Providing an answer, or rather answers, to this question is the goal of *Illness as Narrative*. This book will explore how writers and readers use narratives of illness to make meaning of the experiences of living *at risk*, *in prognosis*, and *in pain*. It will also consider how narratives of illness invite reflection about the purpose and future of literature, the arts, and literary criticism. The academy has long rewarded readings that dismantle literature’s illusions but, with regard to literary and amateur illness memoirs, it is also evident that critics need other options, interpretive approaches that enable them to assemble meaning in the face of life’s fragility. This chapter begins the larger exploration of *Illness as Narrative* by charting the rise of illness narratives and considering how this history brings to the surface difficult questions about the evolution of contemporary criticism—what it has made possible, and what it has excluded.

The Emergence of Illness Narratives in the Twentieth Century

Having observed the remarkable cultural shift from the silence about the 1918 flu and the quantities of writing that appeared with the pandemic of HIV/AIDS, how do we account for the proliferation of illness memoirs in the late twentieth century? What changes occurred historically, culturally, politically, and medically to bring about this transformation in literacy and literature? A patchwork of answers is available in medical, scholarly, and popular writing on health and illness. In the early twentieth century, the flu evaded expression, in part because it spread so quickly and affected so many that it overwhelmed feeble governmental and medical, as well as narrative, responses. As terrifying as the plague was, it generally remained off the front pages of newspapers, where the war remained the primary concern. In an apparent effort to allay anxiety during the peak of the pandemic, journalists throughout the United States and much of Europe downplayed the severity of the virus (Kolata 51–54; Barry 335). In the *New York Times*, for instance, only four front-page articles appeared between August and December 1918, during the height of the outbreak. The strategy of journalistic understatement during the height of the pandemic may ultimately have triggered more alarm among the general public because “what officials and the press said bore no relationship to what people saw and touched and smelled and endured” (Barry 335; see also Kolata). At stake is more than the stories that journalists and editors consider appropriate to publish. The silence extended to other genres of writing.⁹ Catherine Belling writes in a study of fiction about the epidemic, “in 1918 . . . , the story of the self was seldom told in public—or at all, especially if it involved private bodily suffering” (57).

In the aftermath of the outbreak, modernists such as Virginia Woolf, working against a different assumption—that illness is too ordinary to merit representation—began to make everyday life the subject of their art. Seven years after the end of the pandemic, Woolf argued in her essay *On Being Ill*, that the commonness of illness had prevented it from “tak[ing] its place with love and battle and jealousy among the prime themes of literature” (3–4). She titled one version of this essay “Illness: An Unexploited Mine”—a turn of phrase that in 1926 would have suggested *unexploded* mines—that is, land mines—from the recent war. With the war over, Woolf encouraged writers to turn their attention to the hidden drama of the sickroom, which she believed held more literary promise than the military detritus of war. “One would have thought,” Woolf wrote, that “novels . . . would have been devoted to influenza; epic poems to typhoid; odes to pneumonia, lyrics to toothache. But no” (4). The story of the body, it seems, “lack[s] plot” (6). Such a claim ignores the presence of illness in the works of Chaucer, the Brontës, Dostoyevsky, and more.¹⁰ It also disregards the ubiquitous Romantic association of tuberculosis and madness with creativity by suggesting that literature ignores the body, as if it were “a sheet of plain glass through which the soul looks straight and clear” (4). According to Woolf, “English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and the headache” (6). In fact, however, she sees the problem as both the absence of words for embodied suffering and the inability of language more generally to communicate personal experience. Such failures render true comprehension of another’s illness impossible. In the infirmary, naïve illusions about the possibility for sympathy, companionship, and the understanding of others dissipate, and one recognizes not only the profound indifference of the world, but also one’s own insignificance.

There is no evidence that Woolf’s argument about language, plot, and illness influenced the writers of her era. Certainly, no rush of novels, epics, or lyrics about influenza suddenly materialized. In the first half of the twentieth century, however, several types of narratives about illness began to appear regularly in professional medical journals and occasionally in the popular press, including biographical case studies by psychologists and psychiatrists, brief snippets of professional memoirs by nurses, and doctors’ heroic narratives of discovery.¹¹ These were precursors to the patients’ own illness narratives. By the 1920s and 1930s, tuberculosis patients composed and published what historian Sheila Rothman calls “sanatorium narratives” (226). Unlike nineteenth-century autobiographies that might integrate discussions of illness into a larger life story, sanatorium narratives more narrowly depicted “an encounter with disease, with staff, and with other patients” in large, impersonal medical facilities where routines were rigid and physicians aloof (Rothman 227). Anne

Hunsaker Hawkins observes in *Reconstructing Illness*, a study of book-length illness narratives (which she calls "pathographies"), that few such narratives, other than those set in the sanatorium, emerged until the 1950s (xiv). By the mid-twentieth century, however, patients with polio—many of whom were also isolated in institutions—began to publish their stories.¹² At the same time, medical journals printed dozens of articles about the "last illnesses" of famous people, from Katherine Mansfield to Charles, Duke of Albany, and from Mozart to Major Walter Reed.¹³ In addition, the "paperback revolution"—which began in the United States with Pocket Books in 1939—made books more affordable to mass audiences and allowed different genres to become popular and profitable, including the therapeutic narratives of self-help and popular psychology, cousins of today's narratives of medical triumph (Illouz 162).

After 1950, profound changes in the patient-doctor relationship were brought about by the increasing professionalization and specialization of medicine. Modern medicine forced trade-offs for both patients and their physicians. Disease became isolated from everyday life because patients now traveled to physicians' offices and hospitals for diagnosis and care (A. H. Hawkins 11). The ill exchanged intimate relationships with local doctors for improved medical efficacy, even as both patients and physicians recognized that inattention to the patient's subjective experience was a detriment to treatment. Evidence that physicians were not blind to this loss can be found in *When Doctors Are Patients*, a collection of thirty-three case histories by physicians about their own illnesses, published in 1952. In the introduction, the physician-editors, Max Pinner and Benjamin F. Miller, state that their goal is to remind doctors that every disease "affects both body and soul" (xiv). "The patient-physician relation is complex and difficult at best," writes Pinner about his own experience seeking treatment for chronic heart disease. As a patient, he was able to find physicians who were "highly competent and able" and "showed genuine professional and human interest" and yet, he says: "with one or two exceptions, they did not understand the full extent of the help they could have given nor the type of help I had expected. The patient needs more than treatment and reassurance; he wants his physician to take the responsibility upon himself" (24). What Pinner needed most was not a list of rules and restrictions—not the mere exercise of technical knowledge—but rather to be shown "the possibilities for enjoyable and fertile living within new limitations" (25).

The loss of intimacy between patients and their physicians accelerated as medical research radically transformed the profession. The discovery of sulfa drugs in the mid-1930s enabled physicians to fight bacterial infections for the first time. Antibiotics, such as streptomycin and penicillin, were developed in the 1940s and did an even better job. Vaccines helped to control diphtheria,

tetanus, and yellow fever, and later measles, mumps, rubella, and polio. By mid-century in the United States and much of Western Europe, the age of acute disease had come to an end (R. Porter 685). What followed, however, was not an age of health and medical triumph, as was expected. Instead, the industrialized world entered the "age of chronic disease" (R. Porter 685). With medicine's ability to cure infectious diseases, people lived long enough to develop ailments of age and prosperity such as heart disease, diabetes, cancer, and arthritis, and they also lived long enough to reflect on and write about their experiences. Although people were *doing* better after midcentury, they were *feeling* worse.¹⁴ Scholars and other cultural critics therefore began publishing critiques of the medical profession that demonstrated that this matter of "feeling worse" did not represent isolated personal discontent, but rather a general cultural problem. In 1951, Talcott Parsons published *The Social System*, one of the first sociological studies of the modern medical institution, setting the stage for more analyses that focused on the experience of the patient and the weaknesses of the medical enterprise. In *The Social System*, Parsons defined the "sick role"—the theory that the treatment of illness within medical institutions transforms people into patients and inscribes them into a particular social script. The appeal of the sick role to the patient, according to Parsons, is that he or she is released from ordinary social roles and obligations; the danger is that he or she is thus compelled to behave according to the institutional norms of medicine. By the 1960s, patients began voicing Parsons's analysis on their own. Members of the antipsychiatry and women's health movements, as well as supporters of new community health centers and pain clinics, denounced their alienation from practitioners and expressed suspicion that medicine had overreached its authority and "medicalized" life by imposing its expertise and control on intimate experiences, from birth to death (R. Porter 691–93). It is also the case, however, that even as complaints about bureaucratic, institutionalized, and increasingly technological medicine grew more widespread, patients became ever more active medical consumers, eventually seeking out medical treatment for everything from attention deficits to weight loss, issues that were not seen as medical before the mid-twentieth century.

As frustrations with the medical system increased, critical commentaries about contemporary medicine began to reach wider, popular audiences. Among the most enduring and influential of these texts is Elizabeth Kübler-Ross's *On Death and Dying*, which appeared in 1969 and made the case for rehumanizing the processes of dying and grieving. This work, in which Kübler-Ross described what she saw as the five stages of grief—denial, anger, bargaining, depression, and acceptance—contributed to the growth of the hospice movement. *On Death and Dying* was quickly followed in 1970 by the first edition of *Our Bodies, Our-*

elves (under the original title *Women and Their Bodies*), which became the bible of the emerging women's health moment.¹⁵ That same year, the founding document of the field of bioethics appeared, Paul Ramsay's *The Patient as Person: Explorations in Medical Ethics*. Three additional texts from the late 1970s would further prepare the ground for the proliferation of illness narratives. Intellectual gadfly Ivan Illich published *Medical Nemesis: The Expropriation of Health* in 1976, in which he attacked doctors, hospitals, and medical institutions for harming more than healing. Two years later, Susan Sontag's *Illness as Metaphor* came out, which documented the cultural and literary history of myths and metaphors for tuberculosis and cancer. She provides example after example of literature that mythologizes and misrepresents these diseases, assigning to them meanings that stigmatize the sick. In rejecting metaphor, Sontag implies that writing about illness should be a scientific and intellectual endeavor rather than a literary one.¹⁶ Finally, Norman Cousins published *Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration* in 1979. This text combines Cousins's own illness narrative with an argument that the interconnection of mind and body is damaged by the dehumanizing experiences that are so common in medical institutions. To assist his own recovery from a debilitating rheumatic disease, Cousins took massive doses of vitamin C and checked himself out of the hospital and into a hotel. There, the story goes, he obtained a film projector, watched Marx Brothers movies and other comedies, and laughed himself back to health. Cousins thus concludes that a cold, mechanized, soulless hospital "is no place for a person who is seriously ill" (31).

Due to the popular success of books like these, by 1980 society was poised for the emergence of what critic Lisa Diedrich calls "the politicized patient" (26). Beginning with the women's health movement of the 1970s, Diedrich observes, patients and writers began to "challenge the structures and structuring of illness from the patient's side of the doctor patient binary" and to "present affective histories that are attentive to the rhetorics and practices of politics" (27). Women's health activists called for women to liberate themselves from the masculine medical establishment by becoming knowledgeable about their own bodies, particularly with regard to reproductive health. In the spirit of this movement, in her memoir *The Cancer Journals*, poet Audre Lorde refuses to accept breast cancer and mastectomy as a loss; instead she writes about her illness as an opportunity to redefine her body, her self, and her voice.

Then came AIDS.

When AIDS first appeared in the United States in the early 1980s, it was immediately defined as the "gay plague" or "gay cancer" and openly discussed as a divine punishment wrought on the culturally marginal communities it disproportionately infected—gay men, intravenous drug users, Haitian immi-

grants, and the urban poor. In this conservative morality tale, AIDS was retribution for the rejection of traditional social norms. To counter the prevailing explanations of the epidemic that were circulating in the mainstream media, early AIDS activists rallied around the slogan "Silence = Death," a call for people to speak up and educate others about the disease. As activist patients grew to know as much or more about their disease than their physicians, they fought for government funding of research and demanded changes in pharmaceutical clinical trials so that more people with AIDS could have faster access to potentially helpful drugs. Patients and their supporters protested, volunteered in health centers, and provided care. And they used writing as a weapon in a cultural battle against homophobia, the disdain of the medical establishment, and the indifference of the government. Activists and people with HIV/AIDS wrote letters, editorials, pamphlets, and manifestos, as well as plays and screenplays, poems, stories, essays, and memoirs. They got the word out.¹⁷

Following the exponential growth of illness narratives about HIV/AIDS in the 1980s and 1990s, the production of other kinds of illness narratives grew even more. This reflects the profound need people have to tell these stories in an era when religious and folk explanations no longer give a satisfying and complete meaning to their experiences, and when biomedicine largely excludes the personal story. In *The Illness Narratives: Suffering, Healing, and the Human Condition*, Arthur Kleinman observes that the sick person and the social group to which he or she belongs have always sought answers to the question, "Why?" and observes, "Whereas virtually all healing perspectives across cultures, like religious and moral perspectives, orient sick persons and their circle to the problem of bafflement, the narrow biomedical model eschews this aspect of suffering much as it turns its back on [the experience of disease]" (29). Historian Anne Harrington similarly notes that conceptual, therapeutic, and existential deficiencies in "physicalist medicine" open a space for the creation of explanatory stories about illness and healing, in particular mind-body medicine (17). Like Kleinman, Harrington maintains, "The physicalist approach to illness falls short, especially for patients, because it denies the relevance of the kinds of questions people so often ask when they become ill: Why me? Why now? What next?" Instead, patients are told, "Your illness has no meaning" (17). In Harrington's view, familiar contemporary narratives of mind-body medicine thus function "as amplifiers of a range of very distinctive moral and social concerns about the costs of modernity" (246). People are drawn to narratives about health and healing—including autobiographical narratives, I would add—in order to work through what she calls "cultural and spiritual dislocations" (230).

The arguments offered by both Harrington and Kleinman add another layer to the complex story about the multiple forces that accelerated the growth

of illness memoirs throughout the twentieth century. Their work suggests that these narratives developed both as acts of resistance to the medical establishment and as necessary complements to modern medicine. If one of the consequences of modernity is that we no longer depend upon traditional explanations for suffering, loss, and mortality, and if doctors' offices and hospitals cannot function as spaces where personal meaning can be developed, then the existential questions about human fragility and significance have to be asked and answered elsewhere.

As this overview of the evolving genre of illness memoirs has shown, throughout the past century Americans have increasingly turned to *writing* to explore the meaning of illness and suffering, and they are more often choosing to make these narratives public in books, magazines, and now online. While critics and reviewers may grumble about the steady accumulation of "misery memoirs," the fact that illness narratives have proliferated is not a sign of a collapse in literary standards. Instead, it is the consequence of a variety of changes in culture, medicine, media, and literacy over the past century, which include medical professionalization; the rise of modern health care; the emergence of the women's movement and the gay rights movement; the etiology of the AIDS virus; the inability of master narratives to give meaning to suffering in the modern era; and technological advances that promote self-publication and the global distribution of information.

Misery Memoirs and Victim Art

As compositions about illness have proliferated in multiple genres, from memoir to journalism, essays, and fiction, and beyond the literary realm to art, film, and dance, no critical consensus has emerged about how to evaluate them. A subset of reviewers and readers sees illness memoirs as acts of testimony about trauma, or at least about the dislocations and transformations caused by disease or disorder. The term "testimony," however, sets a high standard, implying that such accounts should be verifiable and authentic. Few illness memoirs—constructed representations of the interior experience of illness—can fulfill such a standard, however. Those who write about illness, an experience that can break a life in two, face the nearly impossible task that confronts all who write about trauma: how to speak the unspeakable. If illness is beyond expression in language, translation of the experience into words misrepresents, even contaminates, the real event. In addition, because illness narratives provoke affective and intimate engagement, responses that have little currency in academic discussions of the arts and literature, they disrupt critical expectations and typical standards of judgment. Even when such works are written by respected writers such as Harold Brodkey, Anatole Broyard, Maxine Kumin,

Audre Lorde, or William Styron, they may seem to be self-indulgent manifestations of sentiment and goodwill. Other critics emphasize that life writing is a product of ideology and an extension of Enlightenment rationality that places the individual at the center of thought. In this framework, the project of personal writing about illness is doomed before it begins. One could say, in fact, that when such memoirs enter the literary world, these critics expect them to fail both as acts of testimony and as works of literature.

Whatever the critics say about the limits of the genre, however, writers continue to produce these memoirs. At what critic Leigh Gilmore calls "the limits of autobiography," they continue to test the possibility that a narrative will do meaningful work in the world.¹⁸ This persistence leaves us with a fundamental question unanswered: What alternatives to suspicion are available as readers, especially critics, seek to understand narratives of illness that are overtly cathartic, therapeutic, or personal?

An array of pragmatic models for responding to narratives about illness exists beyond the mainstream in the medical humanities. In anthropology, for instance, Kleinman's *The Illness Narratives* draws attention to how patients' spoken explanations of disease can differ cross-culturally and offers guidelines for how physicians can do a better job of eliciting and understanding patients' explanations. In psychology, James E. Pennebaker conducts empirical research on the therapeutic benefits of expressing emotions, in particular the benefits of writing about trauma and other unsettling experiences. Although he does not promise that writing is a cure-all, his research demonstrates that the practice of composing provides a means for organizing an understanding of one's life and self, and for gaining insight into uncertainty and the unknown. Both *Reconstructing Illness* by medical humanist Anne Hunsaker Hawkins and *The Wounded Storyteller* by sociologist Arthur Frank catalog the common narrative patterns found in illness narratives. Rita Charon's book *Narrative Medicine* and her Program in Narrative Medicine at Columbia University seek to teach clinical practitioners—doctors, nurses, social workers, and therapists—to develop an active textual and cultural knowledge of narrative in order to "improve the effectiveness of care by developing the capacity for attention, reflection, representation, and affiliation with patients and colleagues" ("Mission Statement").

Much of this foundational work in the medical humanities has not, however, gained a foothold in mainstream criticism. In *The Invading Body*, Einat Avrahami observes that the encounter with illness narratives "creates ethical and emotional engagement in a way that affords something beyond a sense of the indeterminacy of meaning" (4). In the academy, however, critics tend to prefer indeterminacy to emotional engagement and imposed ethical obligations. Although an influential core group of scholars, including G. Thomas Couser,

David B. Morris, and Priscilla Wald, write about disability, pain, and narratives of contagion, much of the scholarship in the medical humanities attends primarily to the pedagogical or therapeutic value of writing about illness. Such approaches, in which personal expression is understood to provide an opening to the experience of another, can appear reductive to literary scholars who value complexity over utility. By contrast, medical humanists are more accepting of the emotional and ethical claims writers make on their readers. In other words, they attend to the *uses* of narrative, written, spoken, and received. They focus on writing about illness as a matter of literacy as well as literature.

For some critics, such pragmatic concerns threaten the status of their work, evoking unmistakable outrage and anxiety about the demands of personal testimony and other works that tug on the emotions. Perhaps the most dramatic example of this response is dance critic Arlene Croce's article, "Discussing the Undiscussable." She dismisses the dance "Still/Here" by Bill T. Jones, without having viewed it, as the most egregious example to date of "victim art"—that is, art that demands a personal, emotional response from each member of the audience (17). Jones, an HIV-positive African American choreographer created "Still/Here" as a dance and mixed-media piece that integrated videotaped interviews of people with terminal illnesses into the performance. Although Croce begins her article by stating that she has no plans to review Jones's dance, this does not stop her from condemning the project. "By working dying people into his act," she writes, "Jones is putting himself beyond the reach of criticism. I think of him as literally undiscussable—the most extreme case among the distressingly many now representing themselves to the public not as artists but as victims and martyrs" (16). Croce chooses not to watch performers she "feel[s] sorry for or hopeless about," either because of their "physical deformities" or because they use their race, gender, or sexuality to "make out of victimhood victim art" (17). Decrying Jones for "tak[ing] sanctuary among the unwell" (28), Croce defends the critic and criticism from the threat of the illness narrative, which "forces" sympathy and thus displaces and devalues dispassionate analytical judgment and appreciation (17). "Disease and death . . . are taking over and running the show," she warns, and "the wistful desire to commemorate is converted into a pathetic lumping together, the individual absorbed by the group, the group by the disease" (25). In her view, real, flawed, everyday bodies and the passions they inspire transform artistic expression into a "messianic traveling medicine show" (15).

Croce's argument generated a storm of responses and announcements of a "crisis in criticism."¹⁹ In the world of literary studies where "the death of the author" is a familiar abstraction, it brought to the surface the question of what

to make of an author or artist who is literally dying. Croce's nonreview placed in full view the empathy gap between creators of art about suffering and illness and disinterested critics. She had numerous supporters, among them Susan Sontag, who chided her "choice of occasion," but applauded her criticism of "the scourge of populism wielded by both left and right." She also faced an array of critics, the most forceful of whom was Homi Bhabha, who unveiled the hypocrisy underlying Croce's ideological attack on ideological art: without actually seeing Jones's dance, she assumed that it represented victimhood instead of survival (Berger 48).

In the years since its publication, "Discussing the Undiscussable" has become a common reference point for scholars who work with illness narratives. For them, Croce's article serves as an extreme example of the familiar complaint that contemporary memoir is "self-indulgent and unworthy of attention" (Conway 10).²⁰ Croce's piece and the critical reactions it inspired allow such critics to trace the battle lines and define the critical stakes in discussions of narratives about illness: on one side stands the dispassionate critic who is suspicious of art that elicits sympathy or empathy; on the other is the empathic critic who seeks to acknowledge the suffering bodies at the center of art.²¹

In recent years, with the rise of affect theory, Croce's diatribe against representing physical vulnerability is now recognizable as a radical articulation of the more general distrust of affect in the critical community, which sees emotion as more prone to political manipulation than reason. The concern is that, when public figures such as writers, entertainers, and politicians, evoke positive or negative emotions—from empathy and love to fear, agony, and shame—these feelings serve existing structures of power. Compassion, for instance, has been claimed by politicians across the political spectrum. In his 2000 presidential campaign, George W. Bush advocated a politics of "compassionate conservatism." He used the term to suggest that dependence on free-market economics demonstrated compassion for society as a whole and justified reduction of the social safety net for the disadvantaged. To Bush's opposition, the phrase came to signify a cynical politics that favored the wealthy while obscuring the deepening political and economic divide between the "haves" and "have nots." While Barack Obama does not evoke the stereotype of the bleeding heart liberal, he has repeatedly evoked compassion in speeches leading up to the 2012 election, positioning himself as more compassionate than conservative legislators who demanded cuts to federally supported health care. In contrast to the Republicans, whom Obama depicts as saying the country "can no longer afford . . . to be compassionate," he declares confidence that Americans can be both "competitive and compassionate" (Obama).

One might expect affect theorists to redefine and reclaim words such as "compassion" from blatant political posturing, but they have generally focused their attention on describing how feelings aroused by emotional rhetoric or sentimental literature reinforce political, economic, and social suffering.²² In the essay "Trauma and Ineloquence," for example, Lauren Berlant questions the contemporary idea that testimonial accounts can stand as evidence for suffering or trauma by drawing attention to the sameness of testimonials written to solicit funds for global charities: "we see that they sing the same song; they are stuck in a social repetition; they produce beauty in contrast to understanding, or they produce beauty as a sign that their desires have defeated them, their intimacies betrayed them, their institutional faith mocked them, their optimism humiliated them" (55). When the smoke clears from the proclamation that testimonies are produced by agentless puppets of power, no one is left standing but the critic who sees what the rest of us, caught up in sentiment, do not. Berlant's implied argument here is that we need critics in order to understand how ideological constraints transform sympathetic readings of others' suffering into acts of complicity with the systems that produce that suffering. We need critics, in other words, to reveal how sentimentalism and ideology constrain common readers and writers.²³

Berlant's argument should not be the last word on sympathy and testimony. While critical warnings to pay attention to how affect and ideology function in relation to texts have value, arguments that all testimony about suffering is mere repetition, and that our only hope as readers is to understand our failure to understand, express what I see as the academy's version of "compassion fatigue." Critics, like everyone else in this media-saturated age, are exhausted by the ceaseless supply of representations of pain, violence, and atrocity that come to us via ever more pervasive media, and that are intensified by our postmodern distrust of our own feelings.²⁴ Perhaps *some* emotional responses are distractions from a legitimate understanding of the structural origins of suffering. But a blanket dismissal of testimony and emotional engagement can only be made from a position of distance and privilege. Such a critical stance imposes a falsely absolute divide between everyday experience and critical engagement. It does not serve literary and cultural criticism well as a tool for understanding life's precariousness.

But what options are there other than the didactic humanism of those who see narrative as redemptive or the radical doubt promoted by contemporary cultural and literary criticism? How can literary criticism productively engage with the new genre of the illness memoir? For those whose training and careers have steeped them in the hermeneutics of suspicion, there seem to be few visible and viable alternatives.

Responding to Stories of Illness

As discussed earlier, models of such productive work exist in the study of literature and medicine: in Rita Charon's *Narrative Medicine*, Arthur Frank's *The Wounded Storyteller*, Anne Hunsaker Hawkins's *Reconstructing Illness*, David B. Morris's *The Culture of Pain*, and Priscilla Wald's *Contagious*. Each of these books discusses how embodied experience raises questions that are not central to current critical practices. The theories of narrative set forth in the work of Charon, Frank, and Hawkins respect the irreducibility of the writer's body. The experience of illness, their work demonstrates, finds expression in recognizable forms, yet the familiarity of the narrative patterns does not detract from the urgent work these narratives perform for the writers. These critics argue that we must attend to this meaning and practice in order to understand memoirs of illness. I find in these writers an admirable and refreshing willingness to be accused of unfashionable earnestness. Morris and Wald take a slightly different path. They shift their critical projects toward broader analyses of cultural discourse about pain and epidemics and thereby affirm the argument of the "Biocultures Manifesto" written by Lennard J. Davis and Morris: "Biology—serving at times as a metaphor for science—is as intrinsic to the embodied state of readers and of writers as history and culture are intrinsic to the professional bodies of knowledge known as science and biology" (411). Collectively, this group of writers demonstrates the limits of social constructionist practices that sharply separate the social and the biological. They recognize that culture and biology intersect in ways that can be mutually beneficial.

How and when will such insights influence those critics still committed to a disembodied criticism? There are indications that such change has begun. Bruno Latour, who built his reputation in science studies as a social constructionist, has lately called for a reconsideration of the goals of criticism, particularly criticism's focus on emancipating the general public from false beliefs (227). In "Why Has Critique Run Out of Steam? Matters of Fact to Matters of Concern," Latour maintains that critique has too often been reduced to the act of "ceaselessly transforming the whole rest of the world into naïve believers, into fetishists, into hapless victims of domination," while simultaneously portraying that behavior as caused by powerful structures whose composition has not been thoroughly examined (243). Critics working in this vein decry trust in religion, fashion, and other conventions, explaining that human behavior is properly understood to be the effect of factors such as economics, discourse, systems of social power, or genetics (238). Latour now finds himself deeply concerned about the relevance of existing models of critique to matters "close to our hearts" (243). He seeks solidarity with his readers, asking if they, too, are

exhausted by how explanations are churned out by the machine of critique, and then declares, "I am, I have always been, when I know, for instance, that the God to whom I pray, the works of art I cherish, the colon cancer I have been fighting, the piece of law I am studying, the desire I feel, indeed, the very book I am writing could in no way be accounted for by fetish or fact, nor by any combination of those two absurd positions" (243). The phrase "the colon cancer I have been fighting" leaps from Latour's list. By including the vulnerability of his own body as a matter as significant as faith, art, desire, and creative work, Latour repeats, with a difference, Virginia Woolf's argument from *On Being Ill*. While Woolf called for writers to acknowledge the importance of illness and embodied experience in epics, odes, and lyrics, Latour calls instead for scholars to approach matters of concern with new conceptual tools whose purpose is not to "debunk," but to "assemble" (246). Contemporary critique, he asserts, risks becoming irrelevant because it has overlooked experiences, beliefs, and passions that are engaged with but not reducible to the facts of material life (or the material facts of life). Thus, he presents his argument: "the critical mind, if it is to renew itself and be relevant again, is to be found in the cultivation of a *stubbornly realist attitude* . . . a realism dealing with what I will call *matters of concern*, not *matters of fact*. The mistake we made, the mistake I made, was to believe that there was no efficient way to criticize matters of fact except by moving *away* from them and directing one's attention *toward* the conditions that made them possible" (231).

As Woolf did in her essay some eighty years earlier, Latour encourages his readers to participate in a thought experiment. He invites us to reimagine the critic, not as "the one who lifts the rugs from under the feet of the naïve believers, but the one who offers the participants arenas in which to gather" (246). He continues, "The critic is not the one who alternates haphazardly between antifetishism and positivism . . . but the one for whom, if something is constructed, then it means it is fragile and thus in great need of care and caution" (246). He also asks us to imagine the circumstances in which we might *want* critics to address matters of concern we cherish—that is, to conceive of a critical practice that adds to our lived experience rather than stands apart from it (232). The challenge Latour poses is twofold: he wants critics to identify complex matters of concern that cannot be accounted for by existing critical approaches and for critics to allow these matters to enlarge the goals and the scope of criticism.

This critique of critique provides a framework for reconsidering why we write and read narratives about illness and what work these literary and folk narratives do in the contemporary world. In turn, such reconsiderations will bring new questions into view—questions to be addressed in the remaining chapters of *Illness as Narrative*. Does prioritizing concerns about risk, pain, hu-

man vulnerability, and the uncertainty of the future alter the critical project? What might the study of narratives about illness look like if the critic's task were to create intellectual arenas for the gathering of ideas, and to address matters of concern with care and compassion? If narratives of illness challenge critics to "combine a willingness to suspect with an eagerness to listen," how can we best respond to this challenge? (Felski 22). How can we define critical practices that are grounded in everyday life, practices that are rigorous, compelling and, at the same time, socially engaged and thoughtfully empathic? The project of *Illness as Narrative* is to explore and model alternative ways of engaging with matters that are, as Latour says, "fragile and thus in great need of care and caution" (246). I will examine a range of practices that are not central to current critical customs but that emerge in writing about illness and in critical work informed by embodied suffering. Practices such as acknowledgment, care of the self, attention, recognition, and repair point to the possibility of redefining the relationship of writers and readers to the books in their hands and the worlds they inhabit.