Calls from within the field of medicine have asked nurses, doctors, and other health-care workers to become more aware of matters of difference. “[B]ias in health care must be corrected not by medical ombudsmen, or by legislation . . . but by a focus on the individual—individual patients and individual doctors,” Abraham Verghese writes in the article “Showing Doctors Their Biases.”1 Mary Lebreck Kelley and Virginia Macken Fitzsimons’s work teaches nurses to understand cultural diversity in clinical practice.2 Medical humanities programs promote awareness of the social aspects of medicine, and the Association of American Medical Colleges has recently instituted cultural competencies for clinical interaction for the training of medical students.

These are timely and much-needed developments. Yet current efforts to impart understandings of the cultural and cross-cultural aspects of medicine suffer from an important limitation: within a medical system whose currency is diagnosis, difference is often defined through disease. Medical students learn, for instance, that African Americans are more likely to suffer from sickle-cell anemia, that women have a propensity for osteoporosis, and that schizophrenia preferentially afflicts the poor.

This special issue of Literature and Medicine focuses on difference and identity in the context of disease and disability. We explore the complex ways in which notions of disease, disability, and difference are intimately related and in which bodies marked by particular gender, racial, disability, sexuality, and ethnic identities experience disease in specific ways. Behind our investigation lies an assumption that understanding cultures and cultural ideologies is central to understanding bodies and diseases. For instance, osteoporosis is complicated by a number of factors that cannot be explained by individual pathology alone. Access to nutritional resources, cultural dietary practices, and types of labor all influence the manifestation, duration, and even the
visibility of the disease. As another example, the different definitions of epilepsy between Hmong and American cultures, as described in Anne Fadiman’s *The Spirit Catches You and You Fall Down*, arise from divergent assumptions about religion, wellness, disease, spirit, and soul. In her account, the Western medical establishment’s inability to recognize these differences frustrates the well-intentioned efforts of doctors and nurses to treat a Hmong child.

We acknowledge and build upon recent efforts of scholars in the social sciences to examine the centrality of identity to constructions of illness and health. Yet the essays in this issue take decidedly humanities-based approaches to the subject in order to emphasize an awareness of and sensitivity to difference through forms of symbolic representation such as metaphor and narrative. The authors of these essays promote exploration of cultural assumptions about values, normality, and deviance while enabling appreciation for the particular and the idiosyncratic. Taken together, this issue highlights how the humanities are particularly adept at enhancing qualities that all good clinicians must possess in abundance: imagination and the inner resources to confront the unexpected. Along the way, we hope readers will learn to negotiate what academic psychiatrists Alexander Ortega and Robert Rosenheck call the effect of matters of difference “on symptom presentation” and to realize how beliefs about difference shape their own diagnostic perceptions.

One way that the essays in this volume promote new understandings of difference and identity is through the exploration of visual knowledge. Medicine would not be what it is today without a long history of its concepts and competencies being presented, regularized, and disseminated visually. From Chinese acupuncture charts, to Vesalius’s anatomical illustrations, to contemporary MRI scans, medical personnel have used images to train their eyes and sharpen their diagnostic capabilities, all the while acquiring sophisticated skill at interpreting and deploying visual cues. Yet the work of making sense of an image requires more than a mere recording of facts. For example, the knowledge required for comprehending images such as a Chinese yin-yang symbol or an American ultrasound scan depends upon the intricate interplay of history, experience, cultures of representation, and many other factors that help shape modalities of seeing. Scholars such as Sue Sun, Stephen Rachman, Robert Goler, and Sander Gilman tap into this process, in which seeing always includes interpreting, in order to interrogate how visual information can mark differences of race, gender, body type, religion, or ethnicity. These authors call on fields such as art
history, film studies, and American studies in order to unpack ideologies involved in the articulation and explanation of images and representational systems. Along the way, their essays teach readers to become more knowledgeable viewers and to reflect upon the implications of their own positions as spectators.

Another focus of the essays in this volume is the representation of medicine through textual narratives. Writing is a critical, though sometimes overlooked, aspect of medicine, be it in a patient’s chart, a research report on a novel case, a popular article discussing a health issue, an individual’s account of his/her experiences with the health system, or a personal description of an illness. Verghese’s *My Own Country: A Doctor’s Story of a Town and Its People in the Age of AIDS* about life in modern American medicine, Fanny Burney’s account of her mastectomy in early nineteenth-century Paris, a Yoruba mythological tale explaining the origins of disease, Meri Nana-Ama Danquah’s *Willow Weep for Me: A Black Woman’s Journey Through Depression*, and Irvin Yalom’s *Love’s Executioner and Other Tales of Psychotherapy* are but a few examples of the kinds of medical narratives produced within a variety of cultural settings. Oliver Sacks, as is well known, has used narrative and the perspective of the individual as critical components of his clinical diagnoses. Documents as standardized as hospital charts are sites where rhetorical decisions about what to include or exclude—be it the patient’s temperature or his/her way of responding to persons in authority—can shape the nature of the clinical interaction and responses to therapeutic interventions. Addressing this complexity, essays by Tobin Siebers, Susan Squier, Gregory Tomso, David Kirby, and Lisa Diedrich work to uncover how various forms of storytelling are neither historically neutral nor purely individual but rather call upon conventions, genres, and other forms of culturally based modes of expression. Their essays promote awareness of the multiplicity of perspectives and points of view involved in a range of intimate, impersonal, or banal interactions—from boarding an airplane, to unprotected sex, to visiting a physician, to solitary meditation.

History is unfortunately replete with instances in which persons have been pathologized and stigmatized based on externally imposed misperceptions of difference or identity. “Diseases” from hysteria to hypertension to homosexuality, among many others, have been critiqued by historians and clinicians alike for institutionalizing cultural biases as pathologies. As one example of such a critique, Sander Gilman’s essay describes how medical understandings of “[w]hat is considered fat and what obese” have shifted over the course of time in
response to ever-changing and highly contextual notions of an “ideal” body weight. Yet, the essays in this volume work to the opposite effect—to lay claim to the agency of difference and, in the process, expose the ideologies and value judgments of the mainstream. They dissect the anatomy of a hegemonic “common sense” mentality, to cite David Kirby’s discussion of Antonio Gramsci, in which categories of inside and outside, normal and deviant, are formed through subjective consent as much as through objective truth.

Although readers will no doubt find that these essays resonate with each other in even more ways than just described, we have grouped them together to suggest broad categories of difference that our authors incorporate, co-opt, and write against: disability, dis-sexuality, and disembodiment. Each section is framed by a short response from a leading scholar whose reflections are meant to illuminate connections and disjunctures among the texts.

Section one explores identities that are constructed, claimed, assigned, or imposed through the rhetoric of disability. In “Disability as Masquerade,” Tobin Siebers reads disability studies through the lens of queer theory in order to interrogate the epistemology of a potentially different closet. “To pass or not to pass,” he asks, “but do . . . narratives about disability illustrate the conventional understanding of keeping secrets about identity?” Siebers uses Joan Riviere’s 1929 essay, “Womanliness as a Masquerade,” contemporary notions of stigma, the Americans with Disabilities Act, the writings of Joe Grigely and of Irving Zola, and his own experiences of navigating crowded airplane aisles “on wobbly legs” in order to trouble conventional understanding of disabled identity. Siebers’s notion of “invisible disabilities” resonates through Susan Squier’s “Meditation, Disability, and Identity,” which investigates the changes that meditation evokes in disability identity. Squier draws on memoirs by people with disabilities who meditate, accounts of meditation-based therapies for people who are ill and/or disabled, and her own experiences of both disability and meditation in order to explore ways in which meditation catalyzes a shift in the understanding of disability, which grows out of a changed conception of the self. Like Squier, Sander Gilman attends to the tensions between cognitive and corporeal forms of disability in “Fat as Disability: The Case of the Jews.” For Gilman, shifting cultural and historical notions of obesity interweave with beliefs about matters such as race, religion, volition, addiction, disease, and masculinity. He asks, “Is obesity the end product of impairment or is it impairment itself? If it is impairment, what organ is ‘impaired’?” In his response, Thomas Laqueur
brings into focus the social and political implications of disability claims by pointing out the almost unavoidable conflicts between disabled identities and the “categories under which an individual can make claims on the state for medical care, for legal protection, for pensions, for workman’s compensation.”

Section two treats the interactions of difference, identity, and sexuality. In “Bug Chasing, Barebacking, and the Risks of Care,” Gregory Tomso analyzes a form of gay, HIV-positive sex that waves a certain flag at the world. Neither condoning nor condemning practices of unprotected sex, Tomso examines popular representations of bug chasing and barebacking as a way of gaining deeper access to popular and professional debates over the meanings of gay sexuality and epidemic disease. Sue Sun’s “Where the Girls Are: The Management of Venereal Disease by United States Military Forces in Vietnam” is also concerned with the rhetoric of promiscuity, only Sun focuses on a promiscuity that was tacitly encouraged even as it was officially maligned. For Sun, military-sponsored sexual-education films serve as an important introduction into the culture of the American military campaign in Vietnam. She shows how, beneath a rhetoric of public health and education, these films sexualize and reinforce the unequal social and economic power relations between American men and Vietnamese women. The duality of a sexuality that gives its subjects voice and mortally wounds them is also Lisa Diedrich’s concern in “‘Without us all told’: Paul Monette’s Vigilant Witnessing to the AIDS Crisis.” Diedrich engages with the work of Timothy Murphy, Kelly Oliver, and other scholars of witnessing in order to read Monette’s individual and highly personal testimonial of a mass epidemic. “We, the readers of Monette’s work,” Diedrich writes, “are . . . implicated in this process of witnessing; we too must cultivate our response-ability through our reading (at the very least) to those whom our society, in the age of AIDS, has made ‘other.’” In her lyrical response, Sidonie Smith considers how the discourse of sexuality plays into the contemporary regime of human rights “and the identities and differences that regime sets in motion.”

Finally, section three investigates differences and identities of embodiment. The section’s first two essays find common ground in the aesthetics and multiple meanings surrounding nineteenth-century representations of deformity. Stephen Rachman’s “Memento Morbi: Lam Qua’s Paintings, Peter Parker’s Patients” examines a remarkable series of 114 paintings made between 1836 and 1852 by the Cantonese artist Lam Qua depicting the Chinese patients of the medical missionary, Rev. Dr. Peter Parker. The essay addresses the ways in which Lam Qua’s
representations of patients with “mature tumors” serve as complex
documents of cultural confluence and exchange between “East and
West, Orient and Occident, portraiture and clinical documentation,
Christian and heathen, rich and poor.” A continent and a world away,
Robert Goler’s “Loss and the Persistence of Memory: ‘The Case of
George Dedlow’ and Disabled Civil War Veterans” examines the cul-
tural meanings attributed to the American Civil War’s disabled veterans
by analyzing representations of soldiers whose limbs were amputated
as a result of battlefield injuries. Goler uses S. Weir Mitchell’s 1866 short
story, “The Case of George Dedlow,” and the postwar discourse of
amputation to discern shifting narratives of national trauma, personal
trauma, and “the symbolic role assigned veteran amputees in the search
for communal suture.” David Kirby’s “Extrapolating Race in GATTACA:
Genetic Passing, Identity, and the Science of Race” moves from past to
future, and from body to disembodiment, through an analysis of the
human-gene technologies imagined in science fiction cinema. For Kirby,
the 1997 science fiction film GATTACA serves as a jumping-off point for
a discussion of the racialized underpinnings of a world in which “a
person’s only sense of identity comes from his or her genes.” In his
response essay, Joel Howell ties the rhetoric of “distorted and absent
body parts” to that of “idealized and perfect body parts” while consid-
ering “the tension between lofty ideals and the inherent messiness of
life, of medicine, and of health care.”

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Of course, our topic selection in no way exhausts the many
complex ways that notions of difference and identity impact construc-
tions of illness and health. Rather, in unique and creative ways, each
essay in this issue provides a heuristic lens through which to consider
the relationships between individual expressions of identity and com-
munal experiences of difference. Each piece also speaks to the process
whereby individual stories and strategies shape, and are in turn shaped
by, the institutions they seek to transform. “The epistemology of the
closet complicates the usual understanding of passing,” Tobin Siebers
writes in his essay, “because it disrupts the structural binary that
represents passing as an action taking place between knowing and
unknowing subjects.” In understanding the narratives of others, in other words, we ultimately learn to rethink ourselves.

NOTES

7. For more information about this initiative, visit http://www.umich.edu/~pchm (accessed March 19, 2004).