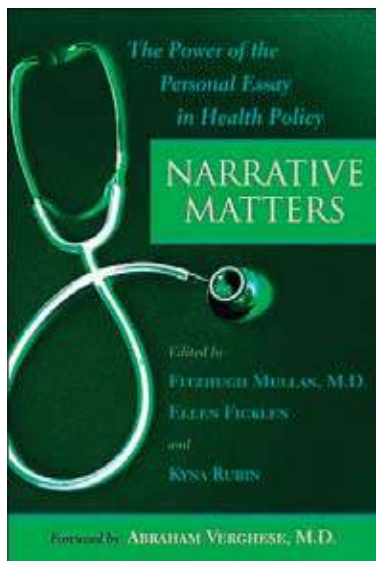


Reviews and reflections

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Narrative Matters: The Power of the Personal Essay in Health Policy

Fitzhugh Mullen, Ellen Ficklen and Kyna Rubin, editors
Baltimore, Johns Hopkins University Press, 2006, 293 pages

Reviewed by Eva Orlebeke Caldera, JD

In accepting the 2006 Nobel Prize in Literature, Turkish novelist Orhan Pamuk described the writer's vocation this way: "A writer is . . . a person who shuts himself up in a room, sits down at a table, and alone, turns inward; amid its shadows, he builds a new world with words."¹ In the essay collection *Narrative Matters*, thirty-eight different authors with varying experiences and perspectives in the world of American health care shut themselves up in a metaphorical room, sit down at the writer's table, and bear witness to the challenges and frustrations of giving and receiving medical care in today's health care environment.

Through their personal narratives, these writers seek to share hard-won



insights into the complex world of medicine, and through the power of their personal testimony, they aspire to alter perceptions and policies—to build a new world with words. Unlike the writer of fiction, however, the contributors to this book (many of whom are already familiar names to readers of medical journalism and memoirs) are engaged in building a world that is not fictional but real—the world of health care and health policy. The narratives they offer are intended both to identify gaps and failures in our current approaches to health care delivery and to advocate practical solutions to a wide range of pressing problems—from racism to health care disparities to end-of-life decision making.

What unifies this book, despite the wide range of issues covered and the diverse voices of its many contributors, is the earnest and soul-searching quality of so many of the pieces. Each of the essays conveys a sincere effort to shine light on a difficult issue that its author has personally struggled to understand and to solve for himself or herself, for a patient, or for a loved one. In documenting their struggles, these writers reveal themselves as human beings—parents, friends, children, spouses—who directly experience the frustrations of what Abraham Verghese, in his foreword to the volume, labels the “mess” of health affairs in America today.

Tying these various essays together is the editorial vision of Fitzhugh Mullen, Ellen Ficklen, and Kyna Rubin, who in 1999 oversaw the launch of the column in the journal *Health Affairs* that is the source of the essays in this book. Likewise entitled “Narrative Matters,” that column was premised on the insight that “the personal narrative could bring a perspective to the quantitative material traditionally published in the journal that would promote understanding and help focus policy deliberations.”^{pxiii} In selecting the forty-six pieces (including three pieces of short fiction) to be published as “narrative matters,” the editors looked for writing that both conveyed

a clear message and told a compelling story that would be representative of the experience of many others. The success of the column inspired the publication of this book, which includes a selection of pieces organized around recurring themes—“The Maddening System: Frustrations and Solutions,” “Trouble in the Ranks: Professional Problems,” and “Drug Resistance: Battling Undue Influence,” to name several of these thematic chapters.

The editors are clearly committed to harnessing the power of individual stories to shape and enliven health policy debates. At the same time, they worry about the “human hazards of subjectivity.”^{pxiv} The book opens with a cautionary chapter pointing out the risks associated with policies shaped by anecdotes as opposed to evidence. An essay by former Massachusetts state legislator John E. McDonough discusses his experience with “Using and Misusing Anecdote in Policy Making.” Another piece, “Out of the Closet and into the Legislature: Breast Cancer Stories,” by communications professor Barbara Sharf, celebrates the role of women's stories in changing the politics of breast cancer, while cautioning that stories can also interfere with objective assessment of treatment options.

Although these concerns about legislating by anecdote are legitimate, they are not necessarily the most important lens for viewing the narratives that follow this opening chapter. The real strength of this book lies in the editors' choice of many pieces that in the words of the writing instructor, “show, not tell.” The best of these narratives are persuasive not because they marshal evidence and arguments for a policy position, but because they give voice to an impulse to humanize medicine and to find honest ways of talking about its daunting challenges.

To that end, many of the authors in this collection share candid and soul-searching stories of providers and patients confronting limits—their own and those of the larger health care system.

Jerald Winakur's brilliant and wrenching essay, "What Are We Going to Do with Dad?" examines systemic issues in caring for the growing elder population through the intensely personal lens of his love for his aging father. Winakur's willingness to pierce the physician's professional veneer, revealing his own vulnerability—as physician, as son, as member of the aging Baby Boomer generation, makes this piece stand out, both as a compelling narrative and as a highly effective piece of advocacy. He offers up unforgettable images of himself spending long nights in the hospital trying to protect and calm his ill, agitated, and disoriented father—"Finally, so that he could get some rest, I got in the bed with him and held him, comforting him as he once—in a long-ago life—did for me." p271 Later, Winakur even allows himself to fantasize, if only briefly, about how he might use the physician's tools to bring closure to his father's (and his own) suffering.

Also impressive in their honesty about difficult—and often unspoken—societal issues are several of the pieces included in the chapter, "Disparity Dilemmas: Stories on Race and Ethnicity." One physician, Neil Calman, describes his struggle to admit and to overcome his racial prejudices and preconceptions in treating minority patients in an urban clinic; his essay, entitled "Out of the Shadow," is a personal meditation summed up by the quotation from Pearl S. Buck that serves as an epigraph to his piece: "Race prejudice . . . is a shadow over all of us, and the shadow is darkest over those who feel it least." p186 Two other physicians, African American Vanessa Northington Gamble and international medical graduate Alok Khorana from India, write of the shadowy mix of visibility and invisibility that they experience as minority physicians. Titled "Subcutaneous Scars" and "Concordance," respectively, their stories offer very different perspectives and personal strategies for thinking through the obstacles of race and racism in health care.

Not all the pieces in *Narrative Matters* dwell on the dilemmas of doctors facing intractable social problems. The voices of patients, families, nurses, and other providers are heard here as well. Patients and families recount their experiences on the receiving end of a seemingly illogical and dehumanizing system that repeatedly stands in the way of obtaining a much-needed wheelchair (Andrew Batavia in "Of Wheelchairs and Managed Care"), or appropriate long-term care (Deborah Stone in "Shopping for Long Term Care"), or adequate mental health treatment (Paul Raeburn in "Acquainted with the Night"). Several nurses reflect on the untenable position they occupy between needy patients and the unrelenting pressures of cost-cutting and bureaucracy; their frustration is abundantly clear in titles like "Accountable but Powerless" (Barry Adams) and "Leaving Nursing" (Ray Bingham).

Still other stories are noteworthy because they offer positive and affirming stories of health care professionals in the role of sincere and committed problem solvers. Janette Kurie's "Where's David?" tells of a team of family practice providers in a small community clinic who observe a strong correlation between frequent no-shows for pediatric appointments and cases of child abuse and neglect. This observation, which begins with a chart review and follow-up for one child with a string of missed appointments, becomes the impetus for a new program at the clinic in which daily chart reviews are used to identify children and families in need of help. Told in a straightforward and unassuming manner, this story of a seemingly simple chart review process is a story of hope—hope that health professionals can develop creative solutions to problems and make a difference in individual lives. Likewise, Darryl Williams's "La Promotora" describes the improving outlook for health care along the impoverished U.S.-Mexico border, achieved through a program to empower local

women to serve as health outreach workers in their communities.

This kind of hope—that positive change is possible and that stories like these can spur such change—is found throughout *Narrative Matters*. As the title announces, stories do matter. Even when some of the contributors express frustration and disappointment, it is seldom because they have given up. Rather, they are writing because they believe that sharing their experiences in this way will contribute to bettering the health care system. As Verghese, himself a noted physician-author, aptly observes in his foreword, they write "to bring about a healing," so that "even when writing can't change the root causes of our malaise (an aging population, rising health care costs, decreasing reimbursement . . .), what it can do is acknowledge the disquiet." ppX-xi Through their stories, these medical professionals and others involved with health care grant us the privilege of sharing their experiences and perspectives. They invite us into the rooms where they turn inward to reflect, to nurture their own humanity, and perhaps to build a new world with words.

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