

■ medical ethics

The Shared Terrain of Narrative Medicine and Advocacy Journalism

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In the still uncharted territory of “narrative medicine,” the early conceptual pioneers have planted a number of boundary stakes and flags in attempts to define the width and breadth of the new discipline, in much the way that new medical subspecialties are defined and legitimized. Thus, depending on whom you read or talk to, narrative medicine is about the writing of stories (narratives, actual or fictional) by medical practitioners as a modality to discover and explore the meaning of practice, or to deepen the human dimensions of the patient-physician relationship. Some have defined it from the patient perspective as the therapeutic use of patient-written stories of personal illness.

But the combined practices of medicine and storytelling (or writing) surely has more to offer than personal introspection, however worthy that goal. Whether it fits within anyone’s definition of narrative medicine or not, skillful storytelling about issues of health and illness has always served a powerful public role, especially that of education and persuasion: to move public attitudes and encourage policy makers to action through the presentation of hard, science-based argument wrapped in the soft flesh of real human stories of suffering and triumph.

In other words, the newly discovered terrain of narrative medicine overlaps the even larger province of advocacy journalism. They come together wherever physicians and other health professionals employ the techniques of narrative to move people toward change—be it toward healthier lifestyles (quit smoking), improved delivery systems (system integration), incremental public or private policy reforms (increased Medicare reimbursements, pay-for-performance incentives), or comprehensive system reforms (single-payer or its alternatives). Call it what you will, this territory is the soapbox on which health professionals can project their own uniquely informed and credible voices to advocate for their vision of a healthier world.

A good number of brave-hearted physicians who have ventured into this overlapping territory have left memorable marks on the wider world. *The Lancet*, the first great medical journal, was founded in 1823 by a London coroner, Thomas Wakley, as a tool for exposing and reforming the despotic and nepotistic organizations running London’s teaching hospitals. He went on to use the journal to great effect in exposing the government’s virtual cover-up of the cholera epidemics of the mid-1800s, causing great consternation among government officials and politicians.¹

More recent physician inhabitants of the territory have included such

giants of literature as Anton Chekhov and William Carlos Williams, who addressed both the mundane and the horrific medical issues of their time through memorable personal essays motivated more by socio-political than aesthetic concerns. Contemporary physician-writers like Robert Coles, Atul Gawante, Abraham Verghese, and Jerome Groopman, writing in the *New Yorker*, the *New York Review of Books* and other mid-to-high-brow consumer magazines, as well as numerous books, have raised the art of advocacy-oriented narrative medicine to the lofty ranks of what’s now popularly known as “literary journalism”—the domain defined by masters like James Agee, John Hershey, John McPhee, Calvin Trillin and Tracy Kidder.

Advocacy-oriented medical journalism has nudged its way even into the sacred pages of the modern professional medical and scientific journals, beginning perhaps with writer-editor Donald Gould’s editorship over the British journals *World Medicine* and *New Scientist* in the 1960s. Gould may be credited with having penned the shortest, and certainly most inflammatory, medical commentary in recent history with his article in the normally objective *New Scientist* on a papal encyclical against artificial contraception in August, 1968: “Bigotry, pedantry, and fanaticism can kill, mame, and agonize those upon whom they are visited just as surely as bombs, pogroms and

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the gas chamber. Pope Paul VI has now gently joined the company of tyrants, but the damage he has done may well outclass and outlast that of all earlier oppressors.²

With far greater reserve, physician-editor John Iglehart opened the pages of the studiously academic and fact-based journal *Health Affairs* to personal, advocacy-oriented medical journalism in 1999 with the launch of the “Narrative Matters” column, edited by physician-writer Fitzhugh Mullan. “The voices of patients, their families, and their caregivers have often gotten lost in the relentless shuffle” of the “big business” that policy-making has become, explained Iglehart in an editorial.³

In the initial installment of the *Health Affairs* column, Mullan himself, already a well-known physician voice for policy reforms, offered a cogent justification for his own journalistic temerity in writing his early book of memoirs, *White Coat, Clenched Fist: The Political Education of an American Physician*: “I was describing what I had seen in the hope that someone might listen and join in an effort to make things better I was telling stories that were pertinent to people’s concerns about health care and, to some degree, a goad to those in charge. My writing was an invitation to change things.”⁴

Anne Marie Todkill, deputy editor of the *Canadian Medical Association Journal*, offered a similar justification for publishing a controversial photo-essay of Cambodian HIV victims by a physician-photo journalist: “Health and disease arise in a setting that is always socioeconomic, political and environmental. When these determinants of health status are particularly evident, and particularly distressing, physicians may find themselves caught by an urge to

look at the broader picture, to investigate, to record, and to send reports from the front that do not fit the mould of conventional scientific medical reporting.”⁵

Today, more than ever, physicians and other caregivers have an unprecedented array of opportunities—and, many would argue, a heavy burden of professional responsibility—to add their voices, and their stories, to the public dialogue about health care. The practice of medicine, as well as the financing and delivery of health care, have entered a period of monumental change, and where it all ends up remains an open question—a question with unfathomable implications for both the profession of medicine and the health and well-being of the American people. Health professionals need not only to enter the fray, but to assert their legitimate right to a leadership role in influencing the outcomes. That job can no longer be left to the likes of the AMA, which continues to represent itself as the voice of American medicine despite a continuing free-fall in both membership and public credibility. Indeed, *JAMA* itself recently featured a thoughtful “Special Communication” article urging greater engagement by individual physicians in advocating for health system improvements in the public arena.⁶

Finally, no one should be intimidated by the lofty, literary claims of “narrative medicine,” nor by the very real accomplishments of the Gawandes, Vergheses, and Coleses, though they make for excellent role models. Local newspaper op-ed and commentary pages are better read and carry more influence in terms of local and state health policy issues—and most health policy is still state-based, not federal—than the *New York Times* and *Wall Street Journal* combined. Letters-to-the-editor

columns are even better read than the editorials and op-eds that appear alongside them, and short (150 words) well-written, highly focused, fact-based and personalized letters from writers with an MD after their name command priority attention from both editors and readers. Within Kaiser Permanente itself, the excellent *Permanente Journal*, published by and for Permanente physicians and other caregivers, offers a unique example of the blending of the objective and the subjective into compellingly human perspectives on medicine, and its editors are eager to nurture new writers.

Picking up the pen of public advocacy does not mean relinquishing the scalpel of one-on-one medical care. The American health care system needs caregivers who are skilled with both tools. ❖

References

1. Wilson AN. The Victorians. New York: WW Norton; 2003. p 35-6.
2. A holy tyrant. *New Scientist* 1968 Aug;39(608): p 221.
3. Iglehart JK. ‘Narrative matters’: binding health policy and personal experience. *Health Aff* 1999 Jul-Aug;18(4):6.
4. Mullan F. Me and the system: the personal essay and health policy. *Health Aff* 1999 Jul-Aug;18(4):118-24.
5. Todkill AM. Boundary crossing: the physician and the photographer. *CMAJ* 2001 Jul 10;165(1):35-6.
6. Gruen RL, Pearson SD, Brennan TA. Physician-citizens—public roles and professional obligations. *JAMA* 2004 Jan 7;291(1):94-8.

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