

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/12873456>

Me and the system: The personal essay and health policy

Article in *Health Affairs* · July 1999

DOI: 10.1377/hlthaff.18.4.118 · Source: PubMed

CITATIONS

12

READS

75

1 author:



Fitzhugh Mullan

George Washington University

175 PUBLICATIONS 4,847 CITATIONS

[SEE PROFILE](#)

Some of the authors of this publication are also working on these related projects:



Global Health Service Partnership [View project](#)



World Health Organization [View project](#)

Health Affairs

At the Intersection of Health, Health Care and Policy

Cite this article as:

F Mullan

Me and the system: the personal essay and health policy
Health Affairs, 18, no.4 (1999):118-124

doi: 10.1377/hlthaff.18.4.118

The online version of this article, along with updated information and services, is available at:

<http://content.healthaffairs.org/content/18/4/118.citation>

For Reprints, Links & Permissions:

http://healthaffairs.org/1340_reprints.php

E-mail Alerts : <http://content.healthaffairs.org/subscriptions/etoc.dtl>

To Subscribe:

<http://content.healthaffairs.org/subscriptions/online.shtml>

Health Affairs is published monthly by Project HOPE at 7500 Old Georgetown Road, Suite 600, Bethesda, MD 20814-6133. Copyright © 1999 by Project HOPE - The People-to-People Health Foundation. As provided by United States copyright law (Title 17, U.S. Code), no part of *Health Affairs* may be reproduced, displayed, or transmitted in any form or by any means, electronic or mechanical, including photocopying or by information storage or retrieval systems, without prior written permission from the Publisher. All rights reserved.

Not for commercial use or unauthorized distribution

Me And The System: The Personal Essay And Health Policy

*Writing is an invitation to change things, to battle mortality,
and to connect the little picture with the big.*

BY FITZHUGH MULLAN

BACK IN 1972, WHEN I FIRST SET ABOUT RECORDING my experiences as a “radical” medical student at the University of Chicago and as a resident in the Bronx, a fellow activist challenged me. “Where do you come off writing your memoirs?” she asked with an in-your-faceness characteristic of the time. “Who do you think you are, anyway? Fidel or somebody?” I struggled with that one. What egotistical urge had driven me to write? Was it vanity or was it hubris? I am sure that there was a bit of arrogance underlying the desire to tell my story—as there has to be for anyone recording a memoir. If, after all, the memoirist doesn’t think he/she has an important tale to tell, there is little likelihood of persuading anyone else of its significance. But the sentiments that prompted me and others to write in the first person go well beyond the venal and the self-promotional.

I wrote, first of all, because I thought I had lived through events that were worth recounting—big events and small ones. I had marched with Martin Luther King Jr. in Chicago shortly before his death and had been “liberated” by Puerto Rican militants, the Young Lords, when they took over Lincoln Hospital in the Bronx a few years later. I had campaigned on behalf of a classmate against a medical school policy that required him to shave his beard on pain of expulsion; and I had felt a man’s bowels grow cold after a failed emergency operation to stem the flow of blood from his ruptured

Fitzhugh Mullan is a physician and a clinical professor of pediatrics and public health at the George Washington University and a staff physician at the Upper Cardozo Community Health Center. He has served as director of the Bureau of Health Professions in the U.S. Department of Health and Human Services and as director of the National Health Service Corps and has written extensively about his experiences as both doctor and patient. He is a contributing editor to Health Affairs and the editor of the “Narrative Matters” section.

aorta. I wanted to tell about these things because they were important to me and because I thought that they would speak to other people as well. For me and, I believe, for others, generous instincts—the urge to record, to share, and to explain—are at the heart of the personal essay. “I was there; you should have seen it,” are sentiments that drive the memoirist. I wanted people to know what had happened in the Civil Rights movement, in medical school, and in some very tough hospitals in the Bronx. I wanted what I had lived through to make sense to them. Chastened but not deterred by my colleague’s reproach, I went on to write a book called *White Coat, Clenched Fist: The Political Education of an American Physician*, a long personal essay about those earlier years.

Goading Those In Charge

HAD SOMEONE ASKED THEN IF I WAS WRITING about health policy or to affect health policy, I probably would have said no. Yes, I was writing to inform people, to persuade them of the need for reforms, but I didn’t see myself as delivering a blueprint for change; nor did I see myself talking to the politicians and policymakers per se. I was describing what I had seen in the hope that someone might listen and join in an effort to make things better. And yet my belief was that what I had experienced was representative of what went on elsewhere and that it should be of interest to people outside of my immediate world. In retrospect, I was indeed writing to influence policy. 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.

In the years since *White Coat*, I have continued to write on a regular basis—commentaries, health policy articles, book reviews, and history. Time and again, though, I have returned to the genre of that first volume, the personal essay. Sometimes in short columns and sometimes at book length, these essays have drawn on my own life to document and dramatize the quandaries and opportunities inherent in our system of health care. I have come to believe that the first-person narrative is an important art form in health and a potential player in the making of policy.

A second reason I write personal essays is common, I think, to

“Writing makes a record, a mark on the world, no matter how small. One’s written words become one’s offspring.”

many people who write: the battle against mortality. Writing makes a record, a mark on the world, no matter how small. One's written words become one's offspring. The stories and their messages will

“I buffered myself against fear and uncertainty about my cancer by considering that I was about to undertake an assignment in a dangerous land—and report back about it.”

live on as evidence of one's presence on the planet and engagement with life. This instinct calls on people to write about their work. Although he was best known as a poet, William Carlos Williams left an eloquent record of personal essays about his work as a general practitioner in Paterson, New Jersey, during the middle years of the twentieth century. Lewis Thomas wrote regularly in the *New England Journal of Medicine* and elsewhere about his life as a physician, a scientist, and an administrator. Along the way, he published an essay

called “Illness,” which reflects on his experience as a patient. Indeed, sickness reminds us most aggressively of our mortality and inspires many to put pen to paper. Paul Tsongas wrote movingly of his newly diagnosed cancer and his decision to leave the U.S. Senate in 1984 in *Heading Home*, a powerful narrative about the importance of his personal life—a farewell that proved to be a premature sign-off to his public career. Don Cohodes, a senior policymaker at the Blue Cross and Blue Shield Association for many years, described his battle with terminal cancer in “Through the Looking Glass: Decision Making and Chemotherapy” (*Health Affairs*, Winter 1995), arguing persuasively that heroic measures were good for the doctor but not for the patient.

In 1975 I was found to have a mass in my mediastinum, the area above the heart and between the lungs. Even before the obligatory biopsy was undertaken that proved it to be cancer, I had begun to contemplate writing about what was happening to me. I believe that I buffered myself against fear and uncertainty by considering that I was some sort of journalist about to undertake an assignment in a dangerous land—and report back about it. The “trip” took more than two years and was truly awful. Although my desire to write disappeared completely during that time, it returned when my health improved: *Vital Signs: A Young Doctor's Struggle with Cancer* appeared in 1983, followed by a *New England Journal of Medicine* piece called “The Seasons of Survival: Reflections of a Physician with Cancer.” These essays (one long and one short) said to me and to the world that I wasn't dead and that I had perspectives on cancer and

cancer care learned from my painful journey that might be of use to other people.

Commentaries such as those of Williams, Thomas, Tsongas, Cohodes, and myself offer the personal essayist a voice in life's ongoing debates, an epistolary vote in the ultimate making of policy by people usually removed in time and space from the writer's personal struggle. That vote and the influence it can carry is an important currency for the personal essayist. It is substantive and permanent. It is a little bit of immortality.

“Being back in practice has given me much to write about that connects my daily experiences with the larger world of health policy.”

A third reason that I write is a conscious urge to connect my little picture with the big picture. This may not move all personal essayists, but it motivates me and is at the core of why the personal essay can speak with eloquence to broad issues of common concern. The link between what I experience personally and the forces that govern society frequently seems quite real to me. For instance, what I perceived as the social myopia and the implicit racism that were part of my medical education troubled me, but these were also issues for society as a whole and for medical educators, in particular. More recently, after many years away from patient care while I served as an administrator and a policymaker in the U.S. Public Health Service, I retrained in pediatrics and went back to work at an inner-city clinic in Washington, D.C. This was like getting out of the sky suite and back into the ball game after many years as a general manager. It was exciting and rejuvenating. It was a throwback and it was a new world. A surprising number of things hadn't changed—the patients, the shortcomings of the inner-city system, the satisfaction of practice. Many things, of course, had changed quite a bit, including the numbers of new medications and the advent of managed care. Being back in practice has given me much to write about that connects my daily experiences with the larger world of health policy and with the very issues with which I struggled as a federal policymaker for many years—care for the uninsured, medical education policy, and public health practice. So now I am a practitioner once again as well as a veteran of the land of policy. The essayist in me cries out for the one world to talk to the other, and so I have been writing a series of commentaries based on my clinical work for the *Washington Post* under the title “From the Clinic.” These pieces are not health policy proposals in any finite sense but are written with an eye to a reader-

ship populated with politicians and policymakers.

The personal essay as a policy piece has a strong tradition in medicine. Atul Gawande, writing “When Doctors Make Mistakes” this year in the *New Yorker*, and David Hilfiker, writing “Facing Our Mistakes” in the *New England Journal of Medicine* some years ago, raise the difficult and troubling issues about physicians’ shortcomings as

“The writing of the personal narrative is not without hazards. Our own spontaneous inner voices do not always make good copy.”

seen in their own practices. The eloquence of these candid reflections and the fact that this is an area about which few physicians write combine to make these narratives classics. Abraham Verghese has earned literary accolades for his autobiographical writings that intertwine his medical work and his personal life. In his first book, *My Own Country: A Doctor’s Story*, Verghese serves as the reader’s guide on a

tour of human immunodeficiency virus (HIV) as it arrived in rural America. Over and over again, that tour invites the reader to consider his own responses to acquired immunodeficiency virus syndrome (AIDS), both as an individual and as a member of society. Verghese’s story brims with health policy implications. Robert Coles has practiced what might be called the “personal documentary” as a variant on the personal essay in his Pulitzer Prize-winning *Children in Crisis* series. Coles uses a documentary approach to depicting children in various settings but remains a prominent presence throughout the accounts; his surmises about the children and their problems are lost on no reader.

Natural as it might seem as an art form, the writing of the personal narrative is not without hazards. Its very spontaneity can be a problem. To work, the essay must be an intimate document in which the writer shares observations and thoughts with candor. Yet our own spontaneous inner voices do not always make good copy. They can wander, suffer from mean-spiritedness or naïveté, groan under the load of ego, or arrive on the page as trivial despite our previous belief that they were visionary. This problem is compounded because the personal essayist writes not only about himself but about other people. The essayist must find a voice that is candid enough to sustain the personal quality but is simultaneously fair to others involved in the story—patients, spouses, family, and colleagues. Calibrating the role of the “I” in the first person is difficult as well. First-person narratives are effective because the reader wants to see inside the life of another person, to compare lots, to identify with or,

on occasion, reject being identified with the writer. Yet “I” and “me” can easily become oppressive, turning the reader off and undercutting both the art and the import of the piece. The best first-person essays are unobtrusively first person, creating a comfortable atmosphere for the reader where the message of the narrative is not obscured by the personality of the messenger.

The Power Of Anecdote

WRITING ABOUT ONE’S OWN EXPERIENCE is an exercise in subjectivity. The very power of the personal essay comes from the view of the world as seen through the eyes of the writer who is unapologetically the arbiter of fact and significance in the narrative. The circumstances reported and the valence they are given are the sole and unchallenged domain of the writer. Anecdote, attitude, prejudice, and point of view are prominent and important components of the personal essay. Although personal observation holds a time-honored place in the history of science, the subjective characteristics of the personal essay are not prominent values in the science of today, nor are they part of the growing efforts in the field of health policy to make decisions based

“The report of life events from an unabashedly subjective vantage point remains a powerful tool for focusing the human mind.”

remains a powerful tool for focusing the human mind. The historian and health policy commentator Dan Fox is fond of saying that, for better or worse, “The plural of anecdote is policy.” The “Harry and Louise” anti-Health Security Act television ads of 1994 are potent examples of the use of anecdote (out of context, synthetic, and dramatized, to be sure) to sway public opinion about health policy. Vignettes about health maintenance organizations (HMOs) in the movie *As Good as It Gets* and conflicts over HIV disclosure policy in the television drama *ER* often engage public attention on health policy issues more effectively (this is not to say, more accurately) than the pronouncements of learned commissions, op-ed pieces, and health policy journals.

The question then may well be asked about the appropriateness of the personal narrative, with its cargo of subjectivity, in a health policy journal. Health care—giving it, getting it, administrating it, teaching it—is a realm of human enterprise that is often personal, frequently dramatic, and always laced with controversy. It is a rich domain for chroniclers who draw on the personal and the subjective,

“The first-person essay can lend perspective and vitality to issues that are being explored and written about in a quantitative and analytic fashion.”

fiction writers, TV producers, and cinematographers—as well as for the writer of the first-person narrative. The personal narrative is indisputably a compelling vehicle for transporting perspective and opinion about health policy issues. The first-person essay, in fact, can lend perspective and vitality to issues that are appropriately and simultaneously being explored and written about in a quantitative and analytic fashion. Personal reflections can add dimension and depth that will make the

issue both more lucid and more interesting. The challenge for a journal whose principal product is analytic and not literary is to find writers who can steer their way between the hazards of ego and introspection on the one hand and pure editorializing on the other. The use of peers (providers, patients, administrators, and teachers) to review submissions will do a great deal to refine the selection process and protect against the potential excesses of style or point of view.

Human beings have always had stories—and always will. Health (and health policy) is a quintessentially human realm, and its stories are as vivid and revealing as those from any area of human endeavor. Even as we move to put decision making in health on a firmer, more quantitative basis, our stories can help to maintain perspective and promote wisdom. That is the mission of “Narrative Matters.”