

## IMAGES OF HEALING AND LEARNING

### From Silence into Language: Questioning the Power of Physician Illness Narratives

Amy E. Caruso Brown, MD, MSc, MSCS, and Rebecca Garden, PhD

#### Abstract

Physicians' narratives of their own experiences of illness can be a kind of empathic bridge across the divide between a professional healer and a sick patient. This essay considers ways in which physicians' narratives of their own and family members' experiences of cancer shape encounters with patients and patients' experiences of illness. It analyzes ethical dimensions of physicians' narratives (such as those by Atul Gawande, Siddhartha Mukherjee, and Paul Kalanithi) and of reflective writing in medical education. It also compares illness narratives written by physicians-turned-patients to those written by patients without medical training in order to explore questions of who ultimately benefits from these narratives and whether these narratives can engender greater empathy between clinicians and patients.

#### Introduction

Binary thinking has been characteristic of Western culture since the time of Plato and Socrates [1], and the same holds true in today's scientific and medical cultures. These dichotomies range from the body and mind and the normal and the pathological to—most importantly in health care—the patient's subjectivity and the physician's presumed objectivity (based in scientific observation and analysis) and the perceived power of the physician and the patient's relative powerlessness and vulnerability. This paper examines ways in which this kind of dualistic thinking can create distance between physicians and patients. This distance, which can develop into a chasm of incomprehension and miscommunication, often derives from fundamental differences in ways of thinking and knowing, beginning with a healthy physician's difficulty imagining an experience of illness.

Physicians are assumed and expected to be healthy in order to care for sick patients, an ironic conception given their high rates of mental illness and suicide [2-4]. The notion of "self-care," a topic of increasing interest in medical culture [5-7], derives from the tendency of physicians to neglect their own health and deny their susceptibility to illness, a tendency driven by a culture that perpetuates the myth of the impervious physician [8, 9]. Popular narratives like the 1991 movie *The Doctor* reflect our culture's struggle with

the effects of binary thinking in health care. The title character, an arrogant surgeon, echoes the popular view that empathy and expertise are incompatible when he tells his residents, “I’d rather you cut straight and cared less.” When he develops throat cancer, his own encounter with illness transforms him into a professional who deeply values empathy [10]. The protagonist in *The Doctor* provides a popular representation of the personal transformation that enables some physicians to both embody the stoic—and, at times, super-heroic—physician and embody, or at least empathize with, the vulnerable patient. Bridging this gap requires a change in thinking, in action, and, importantly, in one’s sense of identity. This essay explores the role that illness experiences and illness narratives can play by promoting humility and engendering a radical shift in perspective.

### **Bridging the Chasm**

The physician who becomes ill and learns empathy from it is a compelling cultural figure who can break down the binary, drawing on her subjective experience of illness to guide her objective thinking—with compassion. Suzanne Fiala, a physician with bipolar disorder, has eloquently observed that “being personally intimate with pain and suffering has been translated into an ability to reach out to my patients at a deep level of connection and caring” [11].

Arthur W. Frank, a medical sociologist who survived a heart attack and then cancer, wrote *At the Will of the Body: Reflections on Illness*, a memoir [12], and *The Wounded Storyteller: Body, Illness, and Ethics* [13], which analyzes others’ illness narratives. In Frank’s work, illness narratives effect the translation that Fiala describes; stories of sickness build connections among those who share the condition of [vulnerability](#). The premise of *The Wounded Storyteller* is that the experience of illness is a form of suffering that engenders empathy: “The wounded storyteller is anyone who has suffered and lived to tell the tale... a fragile human body and a witness to what endures” [14]. The story of illness breaches a chasm that may otherwise exist between the well and the sick and the physician and patient; the illness narrative forms “the common bond of suffering that joins bodies in their shared vulnerability” [15].

Patients—and readers in general—yearn for literary experiences that bridge the chasm between experience and expertise, subjective suffering and objective knowledge. In Atul Gawande’s best-selling book, *Being Mortal: Medicine and What Matters in the End* [16], the physician-author writes about his father’s experience of cancer. This account and the stories of other family members and patients structure Gawande’s exploration of approaches to aging, illness, and the end of life. Here the physician-author’s role as listener and witness to stories forges a connection with his readers. Pulitzer-Prize-winning author and oncologist Siddhartha Mukherjee reinforces story as a bond with patients when he tells journalists that his bestselling book, *The Emperor of All Maladies: A Biography of Cancer* [17], is written for a patient with stomach cancer who told him, “I

need to know what it is that I'm battling" in order to fight [18]. Mukherjee's commitment to bridging the divide involves listening to his patients' stories and collaborating in telling them as a means of healing: "A patient, long before he becomes the subject of medical scrutiny, is, at first, simply a storyteller, a narrator of suffering.... To relieve an illness, one must begin, then, by unburdening its story" [19]. Mukherjee sees medicine as "a narrative form, in which patients tell stories to doctors, and doctors digest and deconstruct and offer a new story to the patient" [20]. This act, creating a bond with patients through storytelling, is fundamental to the discipline of the health humanities and to narrative medicine [21, 22], which view the ability to understand and respond with sensitivity and insight to patients' stories as fundamental to healing.

### **The Sick Healer**

One might conclude, then, that the ideal healer would be the physician who has personal experience with illness and thus the ability to tell the story from the patient's perspective, like Gawande. One possible exemplar is found in the widely acclaimed and posthumously published memoir *When Breath Becomes Air* by physician Paul Kalanithi [23], who wrote of the transformation of power and position wrought by the discovery that he had inoperable cancer. "Instead of being the pastoral figure aiding a life transition," Kalanithi recalls, "I found myself the sheep, lost and confused" [24]. Best-selling physician illness narratives capture the popular imagination with the specter of the heroic physician, the "pastoral figure," as Kalanithi puts it, rendered even more mythically powerful because of being wounded by illness and thus possessing genuine empathy. The fact of Kalanithi's mortality—that he writes fully aware that he will not survive his cancer—serves as an antidote to a traditional barrier to physician empathy, namely, the deeply embedded belief that the role of the physician is to cure and that anything else implies loss of control and failure [25].

Yet Kalanithi, not unlike other nonmedical writers facing unexpected suffering, seeks to situate his intimate viewpoint within a greater tradition of literature and storytelling [26, 27]. In this sense, Kalanithi writes not to share his insights as a physician dying of cancer but to make sense of his life. He is, to paraphrase narrative ethicist Martha Montello, telling a story he can live with [28]. However, Kalanithi's story also provides an important counterpoint to the narratives in Gawande's *Being Mortal*. Gawande and other physicians who have written about encounters with patients and family members at the end of life tend to idealize a certain type of death and a certain type of patient—one who courageously but passively submits to mortality [29, 30]. While it is no doubt true that American medicine has historically failed to help patients set realistic goals when cure is unlikely, Kalanithi's writing creates a space for patients who do not believe that fighting until the end (with the hope of a miraculous cure) and hoping for a peaceful death are mutually exclusive. This is the double-edged sword of physician-as-patient illness narratives—that these narratives may be exalted as the "right" way to approach illness.

## The Role of Narrative in Medical Education

Physician [illness narratives](#) align with the increasingly popular practice in all levels of medical education to encourage empathy through reflective writing in journals, portfolios, “critical incident reports,” and the imagined autobiographies of patients [31-33]. Some health care educators encourage students to write narratives of their own illness experiences in part as a means of counteracting the myth of the impossibly healthy physician [34] and to better recognize the complex embodiment of trainees in terms of not only illness but also race, ethnicity, and gender [34-36], which, along with ability, may be bound up in the myth of the physician or physician-in-training as healthy and otherwise normative. Writing about experiences of illness—their patients’ and their own—can help health care professionals develop the moral imagination necessary to understand and be moved to action by patients’ suffering. Physicians who write about their own illness may develop their capacity not only to empathize with patients but also to cope with personal suffering.

However, writing that focuses on personal experience, whether as a physician or patient, risks becoming an end in itself. Physician illness narratives may also inadvertently promote the ideal of the heroic physician, adding poignancy and courageous empathy to the archetypal characteristics of knowledge, expertise, and strength. Furthermore, physician writers may lack the humility necessary to recognize the limits of their own experiences when trying to understand and empathize with their patients. Physicians will always have more power than their patients in clinical settings, and they wield a significant amount of social capital outside those settings. Their writing, therefore, always holds the potential to pull the focus away from patients rather than to deepen their understanding of them [37]. Writing and publishing about patients should involve an ethical analysis that begins with questions such as who benefits the most and whether the publication comes at a cost to patients [38].

## Conclusion

A fundamental question to ask of this genre is whether physician authors will always expand their own authority, even when writing to empower patients. For those whose social standing and role in the clinical setting grant them influence and control, writing about themselves could, at the very least, distract from the needed focus on patients. Thus it is critical to foreground illness narratives written by nonphysicians, particularly those who frame their experiences, and the writing itself, in explicitly political terms. A famous example of this is Audre Lorde’s *Cancer Journals* [39], which begins with a chapter called “The Transformation of Silence into Language and Action,” an analysis of the harms and benefits, to the author and others, of writing about her experience of cancer. Lorde observes that “I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. That the speaking profits me, beyond any other effect” [40]. She goes on to say that, once she received her cancer diagnosis, she regretted her

former “silences.” She says, “My silences had not protected me. Your silence will not protect you. But for every . . . attempt I had ever made to speak those truths for which I am still seeking, I had made contact with other women while we examined the words to fit a world in which we all believed, bridging our differences” [40]. Lorde reminds us that, while we must weigh the risks of telling our stories—including who tells the stories and how—the greatest harm is silence and the greatest benefit is solidarity. By placing physician illness narratives alongside those of patients without professional medical training, we build bridges across differences through solidarity.

## References

1. Elbow P. The uses of binary thinking. *J Adv Comp*. 2009;13(1):51-78.
2. Aggarwal AK, Thompson M, Falik R, Shaw A, O’Sullivan P, Lowenstein DH. Mental illness among us: a new curriculum to reduce mental illness stigma among medical students. *Acad Psychiatry*. 2013;37(6): 385-391.
3. Eckleberry-Hunt J, Lick D. Physician depression and suicide: a shared responsibility. *Teach Learn Med*. 2015;27(3):341-345.
4. Dobson R. Suicide rate of women doctors in US is twice that of other working women. *BMJ*. 2007;335(7627):961.
5. Sanchez-Reilly S, Morrison LJ, Carey E, et al. Caring for oneself to care for others: physicians and their self-care. *J Support Oncol*. 2013;11(2):75-81.
6. Kuhn CM, Flanagan EM. Self-care as a professional imperative: physician burnout, depression, and suicide. *Can J Anaesth*. 2017;64(2):158-168.
7. West CP, Dyrbye LN, Erwin PJ, Shanafelt TD. Interventions to prevent and reduce physician burnout: a systematic review and meta-analysis. *Lancet*. 2016;388(10057):2272-2281.
8. Edney D. The myth of the invincible doctor. *J Miss State Med Assoc*. 2016;57(1):17.
9. McCredie J. Exploding the super-doctor myth. *Australian Doctor*. October 16, 2007.
10. Haines R. *The Doctor* [film]. Los Angeles, CA: Touchstone Pictures; 1991.
11. Fiala SJ. Normal is a place I visit. *JAMA*. 2004;291(24):2925.
12. Frank AW. *At the Will of the Body: Reflections on Illness*. Boston, MA: Houghton Mifflin; 2002.
13. Frank AW. *The Wounded Storyteller: Body, Illness and Ethics*. 2nd ed. Chicago, IL: University Of Chicago Press; 2013.
14. Frank, *The Wounded Storyteller*, xi-xii.
15. Frank, *The Wounded Storyteller*, xix.
16. Gawande A. *Being Mortal: Medicine and What Matters in the End*. New York, NY: Metropolitan Books; 2014.
17. Mukherjee S. *The Emperor of All Maladies: A Biography of Cancer*. New York, NY: Scribner; 2010.
18. McGrath C. How cancer acquired its own biographer. *New York Times*. November 8, 2010.

[http://www.nytimes.com/2010/11/09/books/09mukherjee.html?\\_r=1&ref=review&](http://www.nytimes.com/2010/11/09/books/09mukherjee.html?_r=1&ref=review&). Accessed November 27, 2016.

19. Mukherjee, 46.
20. Telling the story of cancer. *Zocalo*. January 12, 2011. <http://www.zocalopublicsquare.org/2011/01/12/telling-the-story-of-cancer/events/the-takeaway/>. Accessed December 7, 2016.
21. Jones T, Wear D, Friedman L, Pachucki K, eds. *Health and Humanities Reader*. New Brunswick, NJ: Rutgers University Press; 2014.
22. Charon R. *Narrative Medicine: Honoring the Stories of Illness*. New York, NY: Oxford University Press; 2006.
23. Kalanithi P. *When Breath Becomes Air*. New York, NY: Random House; 2016.
24. Kalanithi, 120.
25. Shapiro J. Walking a mile in their patients' shoes: empathy and othering in medical students' education. *Philos Ethics Humanit Med*. 2008;3:10. <https://peh-med.biomedcentral.com/articles/10.1186/1747-5341-3-10>. Accessed April 3, 2017.
26. Rapp E. *The Still Point of a Turning World: A Mother's Story*. New York, NY: Penguin Press; 2013.
27. Gerson S. *Disaster Falls: A Family Story*. New York, NY: Crown; 2017.
28. Montello M. Narrative ethics. *Hastings Cent Rep*. 2014;44(suppl 1):S2-S6.
29. Hirni K, Carter B. White flag. *Ann Intern Med*. 2015;162(6):453-454.
30. Sacks O. *Gratitude*. New York, NY: Knopf; 2015.
31. Branch WT Jr. Use of critical incident reports in medical education: a perspective. *J Gen Intern Med*. 2005;20(11):1063-1067.
32. Kirkpatrick JN, Nash K, Duffy TP. Well rounded. *Arch Intern Med*. 2005;165(6):613-616.
33. Marshall PA, O'Keefe JP. Medical students' first-person narratives of a patient's story of AIDS. *Soc Sci Med*. 1995;40(1):67-76.
34. DasGupta S, Charon R. Personal illness narratives: using reflective writing to teach empathy. *Acad Med*. 2004;79(4):351-356.
35. Kumagai AK. A conceptual framework for the use of illness narratives in medical education. *Acad Med*. 2008;83(7):653-658.
36. Wear D, Aultman JM. The limits of narrative: medical student resistance to confronting inequality and oppression in literature and beyond. *Med Educ*. 2005;39(10):1056-1065.
37. Garden R. Expanding clinical empathy: an activist perspective. *J Gen Intern Med*. 2009;24(1):122-125.
38. Peterkin A. Primum non nocere: on accountability in narrative-based medicine. *Lit Med*. 2011;29(2):396-411.
39. Lorde A. *The Cancer Journals*. San Francisco, CA: Aunt Lute Books; 1997.
40. Lorde, 17.

**Amy E. Caruso Brown, MD, MSc, MScS**, is an assistant professor in the Center for Bioethics and Humanities and the Department of Pediatrics at Upstate Medical University in Syracuse, New York, where she also co-directs Foundations of Reasoning in Medicine, a required course for preclinical medical students. She earned a medical degree from Emory University, a master's degree in medical anthropology from the University of Oxford, and a master's degree in clinical science from the University of Colorado. She completed residency and fellowship training in pediatrics and pediatric oncology at the Children's Hospital of Philadelphia and the Children's Hospital Colorado.

**Rebecca Garden, PhD**, is an associate professor in the Center for Bioethics and Humanities at Upstate Medical University in Syracuse, New York. She earned her doctorate in English literature at Columbia University and has published in a range of journals including *New Literary History*, the *Journal of General Internal Medicine*, and the *Journal of Clinical Ethics*. She is executive director of the inter-institutional Consortium for Culture and Medicine and president of the Medical Humanities and Health Studies Forum executive committee for the Modern Language Association.

### **Acknowledgements**

With thanks to Lauren Zahn for her editorial assistance.

### **Related in the *AMA Journal of Ethics***

[The Ethical Force of Stories: Narrative Ethics and Beyond](#), August 2014

[From \*Doctors' Stories\* to \*Doctors' Stories\*, and Back Again](#), March 2017

[From Particularities to Context: Refining Our Thinking on Illness Narratives](#), March 2017

[The House of God—Is It Pertinent 30 Years Later?](#), July 2011

["Sickness Is a Place": The Foreign Culture of Illness](#), April 2012

[Tangles: An Illness Narrative in Graphic Form](#), August 2014

[Vulnerability in Physicians' Narratives](#), July 2011

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2017 American Medical Association. All rights reserved.  
ISSN 2376-6980**