

Under the Bright Light: When Celebrities Take Illness Public

Barron Lerner, M.D., Ph.D.

In March 2007, Elizabeth Edwards went public with her battle against breast cancer, joining a long list of famous people who have come forward in recent years to talk about their illness. But unlike Edwards, who is married to former North Carolina Senator John Edwards, people in the public eye weren't always so forthcoming, as Barron Lerner, M.D., Ph.D., documents in his book *When Illness Goes Public: Celebrity Patients and How We Look at Medicine*.

The 2006 book, supported by a Robert Wood Johnson Foundation (RWJF) Investigator Award in Health Policy Research, traces the evolution of celebrities and their relationship with the public and the media around disclosure of serious illness. Here, Lerner examines the impact celebrities have had on Americans' personal struggles with illness, and how those stories have helped shape health care policy. What he sees is a cultural shift—taking what were once considered very private matters and making them stories of great public interest.

“What we've had over the last 60 to 70 years is a real opening-up of celebrity illness,” says Lerner, Angelica Berrie-Gold Foundation Associate Professor of Medicine and Public Health at the Columbia University College of Physicians & Surgeons and the Mailman School of Public Health. In many instances, he says, the telling of these stories has had such a dramatic impact on the American public that ultimately doctors and health policymakers drew powerful lessons from them as well.

In *When Illness Goes Public*, Lerner recounts the experiences of 13 celebrities who faced devastating illnesses, including famed Yankee baseball player Lou Gehrig and actor Steve McQueen. Lerner illustrates how these personal stories changed public perception, and, in turn, influenced thinking about the doctor-patient relationship, experimental treatments, hope and futility, medical errors, the use of medical technology, patient confidentiality, and the stigma of AIDS, among other issues.

Gehrig, for example, was among the first patients whose struggle with amyotrophic lateral sclerosis (ALS, now known as Lou Gehrig's disease) was widely covered in the press. In those days, most journalists who learned of Gehrig's prognosis—that the disease was fatal—kept quiet. But the American public did learn about Gehrig's efforts to fight the disease and undergo experimental vitamin treatments at the Mayo Clinic, planting the seed in the minds of ordinary people that seeking experimental treatments might be an option for them as well, if needed. Later, photographer Margaret Bourke-White chronicled her own experimental brain surgery for Parkinson's disease in *Life Magazine*. While helping to educate the public about the disease, Bourke-White was careful to warn readers that the surgery might not benefit, and could even harm, some patients. Ultimately, her experience with the surgery was mixed; the benefits didn't last, and she required intensive physical therapy for the rest of her life.

Actor Steve McQueen, who was diagnosed with mesothelioma in 1979, hoped to keep the details of his illness secret, but was outed by the *National Enquirer*. He received standard treatment for his cancer, and when that failed, he pursued alternative therapies in California and Mexico. Even though McQueen died shortly thereafter, his story of fighting cancer by seeking unconventional treatments resonated with the public. Because he had consistently played rebels in the movies, “it was easy and logical for Steve McQueen to assume the role of a determined and rebellious cancer patient,” Lerner writes. The power of his story reflected—and perhaps even helped advance—the shifts toward health care consumerism and away from the “doctor knows best” culture of medical paternalism that dominated up to the 1970s.

A National Program of
the Robert Wood Johnson Foundation

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About the Investigator

Barron H. Lerner is the Angelica Berrie-Gold Foundation Associate Professor of Medicine and Public Health at the Columbia University



College of Physicians & Surgeons and the Mailman School of Public Health. Dr. Lerner received his M.D. from Columbia in 1986 and his Ph.D. in history from the University of Washington in 1996.

His latest book, *When Illness Goes Public: Celebrity Patients and How We Look at Medicine*, was published October 2006 by the Johns Hopkins University Press. Significant funding for this project came from the RWJF Investigator Awards in Health Policy Research program as well as the Greenwall Foundation and the National Library of Medicine. The book won the Washington Irving Book Award, and was named Outstanding Academic Title by *Choice*: Current Reviews for Academic Libraries.

Dr. Lerner's previous book, *The Breast Cancer Wars: Hope, Fear and the Pursuit of a Cure in Twentieth-Century America*, published by Oxford University Press, won the William H. Welch Medal of the American Association for the History of Medicine. The book, which was also funded by the Robert Wood Johnson Foundation, was named one of the 26 most notable books of 2001 by the American Library Association.

In addition to his research, Dr. Lerner teaches bioethics at Columbia, where he is on the faculty of the Center for the History and Ethics of Public Health and the Center for the Study of Society and Medicine. Dr. Lerner is also an internist, seeing patients in general medicine clinic.

Then there's the story of Libby Zion, an 18-year-old college student who died tragically in 1984 at New York Hospital while being cared for by medical residents. Her father, Sidney Zion, an investigative journalist and former attorney, publicized what happened to his daughter and campaigned tirelessly against the reliance of teaching hospitals on overworked and inadequately supervised residents to provide patient care. Libby Zion's death and her father's crusade are frequently credited with leading to the reform of resident work hours and supervision, first in New York State, and later nationwide.

Lerner also depicts the transformation of celebrity patients into patient activists. For example, Elizabeth Glaser, wife of actor Paul Michael Glaser, and top tennis player Arthur Ashe, who, Lerner writes, were "outed as HIV-positive by an aggressive media," became outspoken advocates for AIDS research and funding. Through her relentless lobbying efforts, Glaser helped increase the National Institute of Health's budget for pediatric AIDS research from \$3.3 million to \$8.8 million. Ashe created a foundation to support educational programs and research, and used public appearances to address the stigma of AIDS and the need for better access to care.

Some stories capture public attention after they've made it to the silver screen. Lorenzo Odone was 5 years old when he was diagnosed with adrenoleukodystrophy (ALD), a fatal neurological disorder. His parents embarked on a public crusade to find a cure that would save their son's life. Their saga was portrayed in the 1992 film *Lorenzo's Oil*. The case highlighted the tensions created when patients—especially children—are dying, effective treatments are lacking, and families are desperate.

Lerner acknowledges the potential for stories of the sick and famous to spread misinformation and false hope among the public. Yet he also sees them as opportunities to open discussions among doctors, patients, and payers about treatment options. "If a celebrity has a right to push the envelope [for treatment options], so do other people as well," he says. Although patients need to be reminded that these anecdotal stories have limits, he argues that the scientific and medical community, in its zeal for evidence-based medicine and randomized controlled trials, shouldn't dismiss the lessons from these stories. "Individual stories remain as powerful as ever, despite what the experts and scholars say," Lerner writes.

Publications

Barron Lerner is the author of several books and publications on health care and disease:

- Lerner BH. *When Illness Goes Public: Celebrity Patients and How We Look at Medicine* (Johns Hopkins University Press), 2006.
- Lerner BH. Crafting Medical History: Revisiting the "Definitive" Account of Franklin D. Roosevelt's Terminal Illness. *Bulletin of the History of Medicine*, 2007; 81, 2, 386-406.
- Lerner BH. Remembering Berton Roueche—Master of Medical Mysteries. *New England Journal of Medicine*, 2005; 353, 23, 2428-31.
- Lerner, BH. McQueen's Legacy of Laetrile. *The New York Times*, 2005, Nov 15.
- Lerner, BH. Hope and Reality Lou Gehrig's Way. *The New York Times*, 2005, April 19.
- Lerner, BH. In an Unforgettable Final Act, a King Got Revenge on His Killers. *The New York Times*, 2005, Jan. 25.
- Lerner BH. *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America* (Oxford University Press, USA), 2003.

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