

When illness goes public: *Celebrity patients and how we look at medicine*

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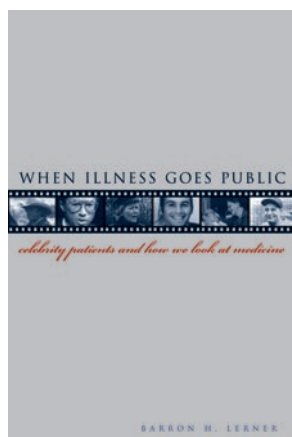
Book Review

In *When illness goes public: celebrity patients and how we look at medicine*, Barron H. Lerner, a physician, medical ethicist, and historian, has investigated the change during the last 70 years in how we in the United States view illnesses contracted by famous individuals as well as persons who became celebrities as a result of illness and subsequent treatment. Drawing from media reports, newspapers, newsreels, movies, autobiographies, biographies, and scholarly collections of individual's papers in addition to his own interviews with both family and friends of his subjects, Lerner offers a superb volume rich with thorough and entertaining recollections and other information not previously in the public domain. Lerner identifies Lou Gehrig as the "first modern patient" because he was a celebrity who later become ill. Lerner discusses how, given his celebrity, Gehrig's doctors endeavored to protect him from the knowledge that he was dying from an incurable disease, and Gehrig's condition was not fully revealed to him, or to the public, until very late. The movie about Gehrig's illness, *The pride of the Yankees*, set the standard for subsequent celebrity deaths with its theme of "unabashed heroism and sacrifice in the face of illness." In captivating vignettes Lerner examines how photographer Margaret Bourke-White, Secretary of State John Foster Dulles, President Dwight D. Eisenhower, football player Brian Piccolo, baseball player [...]

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When illness goes public

Celebrity patients and how we look at medicine

Barron H. Lerner

The Johns Hopkins University Press. Baltimore, Maryland, USA. 2006.
352 pp. \$25.00. ISBN: 978-0-8018-8462-7 (hardcover).

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In *When illness goes public: celebrity patients and how we look at medicine*, Barron H. Lerner, a physician, medical ethicist, and historian, has investigated the change during the last 70 years in how we in the United States view illnesses contracted by famous individuals as well as persons who became celebrities as a result of illness and subsequent treatment. Drawing from media reports, newspapers, newsreels, movies, autobiographies, biographies, and scholarly collections of individual's papers in addition to his own interviews with both family and friends of his subjects, Lerner offers a superb volume rich with thorough and entertaining recollections and other information not previously in the public domain.

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In captivating vignettes Lerner examines how photographer Margaret Bourke-White, Secretary of State John Foster Dulles, President Dwight D. Eisenhower, football player Brian Piccolo, baseball player Jimmy Piersall, civil rights lawyer Morris Abrams, and the parents of Lorenzo Odone (notable for their quest to find a cure for adrenoleukodystrophy, depicted in the film *Lorenzo's oil*) were all at the center of cultural changes. In each of their cases, certain themes emerge repeatedly. The concept of *fighting* one's illness — seeking out the most advanced treatments or volunteering for new experimental

therapies — became admirable. Celebrities began to "go public" about their illnesses and treatments and learned that they could mobilize the media to help represent them as they questioned established medicine and lobbied the FDA for change. Often, the patients or their surviving family and friends established a charitable foundation to fund further research into disease prevention or cure and to advise other patients on both physical and emotional aspects of the illness. With time, celebrity activists have often triggered ordinary persons diagnosed with the same or similar illness to become proactive in obtaining knowledge about their disease in order to fight it. As Lerner writes, "But more than providing practical advice, ill celebrities have delivered something else: stories of tenacity, inspiration and hope at a time of crisis . . . compelling and meaningful narratives of resistance."

Lerner continues, "A crucial part of disease activism is the ability to obtain research funding from the government. So is the ability to raise private money to establish disease-specific foundations. And the best way to obtain both types of funding is to have a celebrity face associated with the disease." After conventional therapy for lung cancer failed, Steve McQueen sought alternative, unorthodox cancer treatments — in doing so projecting an image of a man actively fighting cancer. Princess Yasmin Aga Khan, daughter of Rita Hayworth, publicized Alzheimer disease and raised money for further research, in part to deal with her anger over her mother's delayed diagnosis. Both Elizabeth Glaser and Arthur Ashe hid their AIDS diagnoses to avoid stigmatizing their families, but both eventually publicly announced their illness to preempt media disclosure. Both became "moral beacons," establishing private foundations and garnering public funding for improved treat-

ment. An interesting caveat raised in the book is that while a celebrity lobbying Congress can often secure greater NIH appropriations for disease-specific research, this often reduces the amount of research funding available for other diseases, particularly those lacking a celebrity face, particularly in a time when the total NIH budget is not increasing.

In contrast to those individuals mentioned above, some we have come to know were unknown private citizens until their illnesses became public. Barney Clark's receipt of the first artificial heart incited a public debate about experimentation with new technologies. Libby Zion's death sparked her father's angry, passionate reform campaign resulting in graduate medical education changes limiting working hours of house officers and requiring attending physician supervision.

In the current scientific community, randomized trials and metaanalyses are the gold standard for therapeutic interventions. But for an individual patient, the bell-shaped curve can be interpreted in many different ways to support the patient's treatment choices. Lerner clearly shows that both patients and physicians must be aware that inspiring stories of an individual patient may not be universally applicable and as such we must continue working with a system that values scientific inquiry and experimentation governed by informed consent, institutional review boards, FDA review and approval, and adherence to ethical standards. Conversely, the scientific community needs to appreciate that individual cases may provide insights that result in scientific progress.

When illness goes public is a clear, concise, and captivating treatise that holds the interest of lay readers and yet illuminates for medical professionals issues that are important to the individual patient as well as the scientific community.