



Robert Aronowitz at the 19th-century home of Philip Syng Physick. See "Father of American Surgery" on page 31.

Naming What Ails Us

MEDICAL HISTORIAN DIAGNOSES THE SOCIAL CONSTRUCTION OF CANCER

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PHOTOGRAPHY BY LISA GODFREY

What's in a name?

If you were to ask medical historian Robert Aronowitz that question, he'd likely tell you, "Everything." When it comes to getting a diagnosis for a disease like cancer, he says, a whole train of connotations and assumptions and fears comes roaring down the track at you. Much of its freight of meaning had already been loaded and set in motion by centuries of healers and sufferers facing the malady. The social context shaped by that past, he contends, frames our present outlook on cancer and how we try to prevent or cure it.

It seems an odd way for a doctor to talk about sickness. Aronowitz had been a practicing internist and clinical teacher for 10 years at Cooper Medical Center in Camden (N.J.) before coming to the Department of History and Sociology of Science a decade ago. We typically think of cancer as a biomolecular affliction—errant cells and malignant tumors—with a natural history that doctors summon up to explain

the pathology and formulate a prognosis. And there are boxcars of data that the stricken can draw on to make informed decisions about treatment.

What's in a name? Aronowitz might also respond, "Nothing." Names and categories help us organize and make sense of the world. "They're useful fictions," he notes, even if they sometimes name a condition that can kill you. What we call "cancer" is as much the outcome of the "social construction of disease"—changing diagnostic and screening practices, norms for labeling it and prevention messages—as it is a biological object that's "out there" waiting to be diagnosed. It's part natural process and part unnatural accretion of meaning built up in our social memory and institutions by past experiences, understandings and choices. The word "cancer" is just an empty train whose semantic cargo gets loaded aboard as it journeys through time.

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“Everything” and “nothing” are perhaps terms too crude to capture Aronowitz’s thinking about health and illness. “Disease concepts are contingent upon, not reducible to, social factors,” he specifies. He’s fond of toning down statements with qualifications like, “it doesn’t capture all the complexity but” To his mind, it’s as much the uncertainty as the knowledge that should inform how we think about disease and



practice medicine. His clinical experience illuminates the difficulty doctors face when they translate uncertain and imperfect data into a clear course of action, and his scholarly insight tells him that there’s more at play than just numbers and data. “A certain humility is in order here,” he advises.

In the 19th century, cancer was almost always far advanced by the time a tumor grew big enough to be noticed. Efforts to cure it were usually desperate, always dreadful and rarely successful. Now, with sensitive screening technologies, we can detect cancer well before it blossoms into a mass of renegade cells. “In other words,” Aronowitz observes, “we’ve changed what we call cancer by catching it ‘earlier’ and at a more

ambiguous stage.” Doctors and scientists don’t really know which, if any, of the so-called “pre-cancers” will develop into metastatic disease, he says, but the word still bears the heavy baggage of fear and fatality that has long burdened it. Today, when a pre-malignant condition is diagnosed, aggressive surgery and chemotherapy often treat the *risk* of future disease—or maybe they are remedies aimed at fear. “We keep applying the word ‘cancer’ to a lot of things that may not be destined to harm us,” he remarks. “So it might be helpful if the word wasn’t in people’s heads when they have to make decisions about what to do when diagnosed.”

Before he went to Yale medical school, Aronowitz “got seduced by linguistics” and did several years of graduate study at Berkeley. As a medical student, rather than acceding to the usual biomedical strictures, he

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was preoccupied with the complex ways new diseases get negotiated. “It was my background in linguistics that allowed me to go through medical training with an eye toward how we name and classify things, and to question the assumptions people make,” he says. The received beliefs that doctors hold to—in order to practice medicine—would catch and unsettle Aronowitz and start him down some track of reflection that ended up as an essay or a book. “To be honest,” he comments, “it almost always began with something in my medical training or practice that annoyed me—something that seemed just not right.”

He calls it his “Clark-Kent/Superman life”: doctor in a white lab coat by day; tweedy medical historian by night. It’s an imperfect metaphor—he can’t say whether healer or scholar is the superhero—but it suggests how each persona is whispered to from behind by an expert or skeptic secret identity. “It’s much more interesting and challenging to think about how something hard and real like cancer is framed by social forces,” he says. “Cancer is so self-evidently a biological process that a

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lot of people shy away from applying a social-historical approach. It's a third rail, and they're afraid to get burned by doctors who 'really know' what's going on. That's the area I flourish in."

The first book he authored was *Making Sense of Illness: Science, Society and Disease*, a collection of essays and case studies about how we recognize a new disease, label it and drop the name into some familiar category of medical knowledge. He was still a practicing clinician and a night-shift medical historian when he penned it. "On the wards," he wrote, "I was enthusiastic about finally taking care of patients, but I sometimes felt alienated by the medical culture of which I was rapidly becoming a member."

By the time he wrote his next book, Aronowitz had flipped identities from physician to full-time scholar. *Unnatural History: Breast Cancer and American Society* looks at the historical momentum that had built up over 200 years of mostly private suffering and medical care, which now structures our very public experience and fear of increased breast cancer risk.

Starting in the 1930s and 40s, more and more cancer was turning up. But the headline-grabbing statistic that reports one in eight American women will be diagnosed with breast cancer, he cautions, is not a simple indicator of more and worse disease. Reliable figures for breast cancer have been kept since the 1930s. When adjusted for aging, the breast-cancer mortality rate remained constant from then until 1990, when it declined.

Aronowitz is a numbers guy, and those statistics bothered him. "How could we have this incredible increase in the number of people labeled with breast cancer without an impact on mortality?" he wondered. It could be that medical progress—early detection and better treatment—added a counterbalance to increased disease, yielding a "mortality standoff," he reasoned. "A more economical explanation is that we have detected a large amount of disease not destined to seriously harm or kill and, until quite recently, have not made significant progress in treating cancer."

Unnatural History casts breast cancer as a contentious and unstable entity, subject to changing values, beliefs, interests and practices. The book tells the story of change in the lived experience of and ideas about cancer: the rise of aggressive surgery and the backlash against disfiguring radical mastectomies, the development of ever more sensitive detection devices and the emergence of early screening, and today's highly fraught collective obsession with risk. So deep is "cancer

fear" that many more women are seeking surgery for various states of cancer *risk*, he argues. Some are having their healthy breast removed along with the malignant one (a 150 percent increase over seven years) even though there are few data on the survival benefit of such aggressive approaches.

Aronowitz and other medical experts maintain that widespread use of screening mammography has yielded a dramatic increase in the number of cancers found,

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although there's significant "semantic slippage" in a term like "pre-cancer," which categorizes as "cancer" aberrant cells whose future malignancy is uncertain. Together with awareness campaigns trumpeting a pestilence of "women at risk" and calling for constant surveillance and aggressive treatment, these social forces all stoke the fires of cancer fear, a runaway train whose bell clamors for even more surveillance and more aggressive treatments for all stages of disease.

The rails on which the train is running were laid down in the past. "So many of our present dilemmas have their origins in past choices and commitments," he states. "It's the overall momentum of our historical experience that we're living with—technology we've developed, public messages we've decided to put out and labels we've given to things."

According to Aronowitz, changing direction is not a simple matter of doing more studies and parsing more data. Last fall, the United States Preventive Services Task Force recommended that women begin regular breast cancer screening at age 50 rather than 40, a stark breach of the received wisdom of early detection. The task force did not deliver new advice but a second medical opinion. In 1977, the National Institutes of Health became concerned that young women were getting too much radiation. With little evidence that screening younger women saved lives, the NIH called for them to wait until 50 or older before starting regular mammography screenings.

In "Addicted to Mammograms," a *New York Times* op-ed piece, Aronowitz observed, "You need to screen 1,900 women in their 40s for ten years in order to prevent one death from breast cancer, and in the process

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you will have generated more than 1,000 false-positive screens and all the overtreatment they entail.” Despite the numbers, doctors have long screened women in their 40s, women continue to demand early screening and “medical opinion” is divided on the matter. The main concern, he stresses, is not only whether over-diagnosis has very tiny effects or leads to costly over-treatment, but whether it causes outright harm: pointless mutilating surgery, useless and injurious chemo and radiation, needless pain and anxiety. We just don’t know.

Solutions for turning aside the forward thrust of history, Aronowitz suspects, might lie in getting at “upstream” policies and practices that inflame the fear of cancer by blurring “the differences between different points on the cancer-risk-to-terminal-disease continuum. . . . We may need to restrain the way we discover and define cancer and cancer-risk states. We

should split up cancer risk and different types of cancer and not lump them together into one feared territory.”

Separating “cancer” from “cancer risk” and “pre-cancer,” the conjoined triplets loaded into a word we’ve inherited, is pretty tricky semantic surgery. Clarifying what’s in a name might not seem to be a medical procedure that holds much therapeutic or health-policy promise, but that’s where Aronowitz brings in another name. “I think to not talk about fear—and call it ‘fear’—is to ignore the elephant in the room. How much fear is appropriate? It’s these harder things about fear and how knowledge is created and how people understand their bodies and think about cancer that are a large part of the issue.”

“I don’t feel comfortable offering *Dr. Aronowitz’s Guide to the Perplexed*,” he adds. “These are very perplexing problems, and I’m just a messenger of the news—very complicated news.” ♦

FATHER OF AMERICAN SURGERY

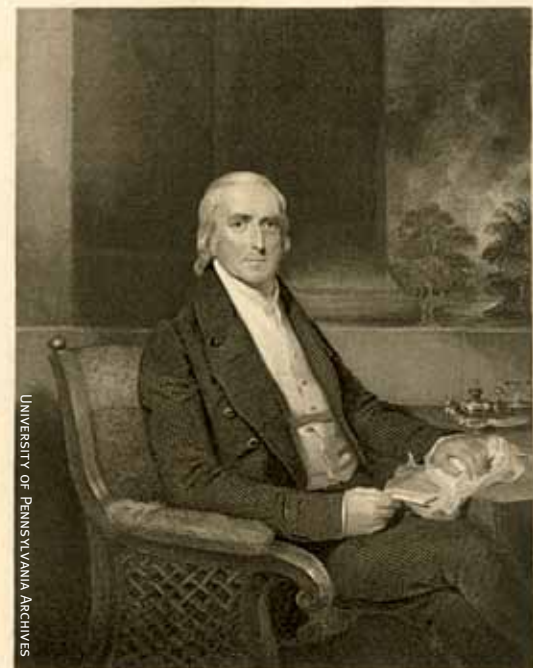
Penn alumnus (1785) Philip Syng Physick was an eminent surgeon who labored to bring Philadelphia’s devastating Yellow Fever epidemic under control in 1793 and again in 1798. Even when stricken by the illness, he remained at his post at the Yellow Fever Hospital at Bush Hill. An innovative surgeon, Physick pioneered the use of the stomach pump, introduced cat-gut sutures, performed the first successful blood transfusion and designed a number of surgical instruments and techniques. Starting in 1800, he delivered lectures on anatomy and surgery at the University of Pennsylvania and in 1805 was appointed to Penn’s first Chair of Surgery.

In *Unnatural History*, Robert Aronowitz discusses Physick’s operation on Susan Emlen for cancer of the breast. Emlen found the breast lump when it was about the size of a partridge egg but opted first for nonsurgical treatments more in line with notions of humoral imbalance, the prevailing medical paradigm for understanding and healing illness. “I knew Dr. Physick’s preference of a surgical operation in such cases,” she wrote to her father, “and I had not yet suffer’d enough to endure the thought of so terrible a measure.” The invention of

ether anesthesia was still three decades away.

On June 4, 1814, Physick performed the surgery on Emlen in her home, removing a one-pound tumor from her left breast. The procedure took 25 minutes. “My whole being seemed absorbed in pain,” she wrote. The surgeon informed the family that “the disease had been completely eradicated,” but the cancer would eventually return. Aronowitz surmises that “when the parts were laid open” Physick found the malignancy too advanced and was likely “shielding the Emlens from the disturbing interoperative findings.” Although Emlen tried other remedies, she declined slowly and died five years after the surgery.

“Cancer in the breast was generally defined by its behavior over a sustained period of time rather than its clinical appearance in a single moment,” Aronowitz writes. “It was a disease that often began as a localized lump but quickly or slowly caused much more harm. Along with its emphasis on the idiosyncratic and contingent nature of health and illness, this definition meant that the cancer diagnosis was often haltingly and flexibly attached to individuals, revealed in the course



PHILIP SYNG PHYSICK, M.D.

Philip Syng Physick, M.D. (1768 -1837), A.B. 1785, autographed portrait

of time and often only at the end of life. The inability to cure cancer was a defining feature in this way of understanding the ailment, so much so that if surgery resulted in an apparent cure, surgeons often believed that they had removed a non-cancerous lump.”

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