

Be Prepared

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I don't blame people for not knowing how to engage with a person with cancer. How would they? Heck, I hadn't either. Despite the fact that each year 70,000 Americans between the ages of fifteen and forty are diagnosed with the disease and that incidence in this age group has doubled in the last thirty years, many of my friends in their thirties have never had to deal with it on a personal level.

I remember when my cousin Elise was undergoing chemotherapy treatment while in her early thirties. When I met her I couldn't even mention it, couldn't (or wouldn't, or didn't) say that I was sorry or ask her how it was going—even though it was so obviously the thing that was going on. I was thirty-five for God's sake, a grown-up, a professional, a parent, and cancer was so unthinkable that I couldn't even acknowledge her disease. When my former partner's sister showed up at our house all bald after her chemotherapy, my only remark was, "Hey, you could totally be a lesbian." I was terrified, or in denial. More likely I had picked up the culture of stigma and this disabled me from giving genuine acknowledgment. But whatever sympathetic spin you want to put on it, I sucked in all the ways that I had to learn how to deal with later. Indeed, an assumption of exceptionalism was only the flip side of my own shame.

Fantasies of agency steep both sides of diagnosis. On the "previvor" side, images continually tell us that cancer can be avoided if you eat right, avoid Teflon and smoking, and come from strong stock. Alternatively, tropes of hope, survivorship, battling, and positive attitude are fed to people post-diagnosis as if they were at the helm of a ship in known waters, not along stormy and uncharted shores. And yet, so little of cancer science, patient experience, or survival statistics seems to provide backing for the ubiquitous calls for hope in the popular culture of cancer. After all, who would celebrate a survivor who did not stand amid at least a few poor SOBs who fell?

Everyone who has "battled," "been touched by," "survived," been "made into a shadow of a former self," or has been called to inhabit the myriad can-

cer clichés has been asked to live in a caricature. As poets say in rendering their craft, clichés serve to shut down meaning. Clichés allow us not to think about what we are describing or hearing about: we know roses are red. People with cancer are called to live in and through—even if recalcitrantly—these hegemonic clichés by news articles, TV shows, detection campaigns, patient pamphlets, high-tech protocol-driven treatments, hospital organizations and smells, and everyday social interactions. Such cultural venues as marches for hope, research funding and direction, pharmaceutical interests, survivor rhetoric, and hospital ads constitute not distinct cultural phenomena, but overlap to form a broader hegemony of ways that cancer is talked about and that in turn control and diminish the ways that cancer culture can be inhabited and spoken about. Cancer exceeds the biology of multiplying cells. But the paradoxes of cancer culture can also be used to reflect on broader American understandings of health and the mismatch of normative assumptions with the ways people actually live and die. The restricted languages of cancer are not innocent.

For an example of how individuated agency is used in cancer, one might look to the massive literature and movement spurred by Bernard Siegel, which is based in the moral complex of cancer and what he describes as the "exceptional patient." In *Love, Medicine, and Miracles: Lessons Learned about Self-Healing from a Surgeon's Experience with Exceptional Patients*, Siegel writes about having the right attitude to survive cancer.¹ In Siegel's view and its variants, surviving cancer becomes a moral calling, as if dying indicates some personal failure. Siegel-style literature offers another form of torture to people with cancer: Did my mind declare war on my body? Am I a cold, repressed person? (Okay, don't answer that.) This huge and punishing industry preys on fear as much as any in the cancer complex and adds guilt to the mix. As one woman with metastatic colon cancer said on a retreat I attended, "Maybe I haven't laughed enough. But then I looked around the room and some of you laugh a lot more than I do and you're still here." She died a year later, though she laughed plenty at the retreat.

It's no wonder that shame is such a common response to diagnosis. The dictionary helps with a description of shame: "The painful emotion arising from the consciousness of something dishonoring, ridiculous, or indecorous in one's own conduct or circumstances, or of being in a situation which offends one's sense of modesty or decency."² Indeed, cancer does offend. People in treatment are often advised to wear wigs and other disguises, to joke with colleagues; they are given tips on how to make others feel more at ease. One does want to present decency, to seem upbeat. And so do others. A quick

“you look good,” with a response of “oh, thanks,” offers a welcome segue to the next discussion topic and enables a certain propriety to circumscribe the confusion of proper responses to illness, to the stigma embodied by the possibility of a short life and a painful death. One person with metastatic disease calls herself, semi-facetiously, “everyone’s worst nightmare.” Others speak about how hard it is to see the celebration of survivors while knowing that they themselves are being killed by the disease.

Social grace is a good thing. But given the scope of the disease—half of all Americans die of it and many more go through treatment—one might wonder what or whom such an astonishing cultural oversight serves. After all, how can cancer, a predictable result of an environment drowning in industrial and military toxicity, be dishonoring or indecorous? I don’t mean its side effects; the physical breakdown of the body is perhaps definitive of the word “indecorous.” But these pre- and post-diagnosis calls to disavowal can help illuminate the ugly underside of American’s constant will to health, its normative assumptions about health and the social, individual, and generational traumas that it propagates. Expectations and assumptions about life span and their discriminatory and generational effects offer but one of many venues for such an exploration.

Survivorship in America

Perhaps it’s a class issue, but I didn’t really think about survival until I was called to consider being in the position of the one who might *be* survived. I was just tootling along until I was invited by diagnosis to inhabit this category, to attend retreats, camps, and support groups, to share an infusion room—to do all kinds of things with many people who have not, in fact, survived cancer—and thus to survive them at their memorial services, the garage sales of their things, and in the constructing and reading of memorial Websites and obituaries.

To be sure, cancer survivorship (as opposed to either cancer death or just plain survival) comes with its benefits. I got a free kayak, albeit with a leak. When things are going really wrong I think about how my life insurance could pay for some cool things for my kids, or that maybe I don’t have to worry about saving for a down payment since in order for a home to be a good investment you should really plan to live in it for five years. Sometimes, when you find yourself buying into those cancer mantras of living in the moment, you can look around from a superior place at all the people scurrying around on projects you have determined do not matter—and then

go and do the laundry or shop for groceries, just like everyone else. Or like Bette Davis does in the movie *Dark Victory* as she dies of a brain tumor; you can consider yourself the lucky one, not having to survive the deaths of those you love. You have that strange privilege of being able to hold the materiality of your own mortality up against every attempt to make value stick. You may wonder, as I do, how anyone survives the death of a parent or a sibling or a close friend or lover—the things that are purportedly normal life events—until you go through it yourself.³

On the other hand, it may be easy to devolve into the narcissism of unremitting fear. I like to keep in mind what a driver once told me when I asked him what it was like to drive celebrities such as Oprah Winfrey around New York. He said, “They like to think they are important. But after every funeral I’ve been to, people do the saaaaame thing. They eat.”

The doctor survives the clinical trial, the child survives the parent, the well survive the sick. But how have we come to take this survivorship for granted, as something to which we are entitled? Even a century or two ago there would have been a good chance that several of us would have died in childbirth or of some illness. Devastating as it may have been, we would have expected this. And we don’t exactly live in a medical nirvana. The United States is not even in the top ten for the longevity of its population. In fact, the United States is missing from the top twenty or even thirty for longevity in the world. In some studies, it’s not even in the top forty.⁴ Despite this statistic, the United States spends more than any other nation on health care. Part of Americans’ dismal life expectancy results from the broad lack of access to health care as well as the broader and well-documented discrimination in health care against the usual suspects: African Americans, women, younger people, and queers. But other factors that affect even those with excellent access to excellent care play in as well: the high levels of toxins in the environment, including those in human and animal bodies; cigarettes; guns; little oversight for food, automobile, and other product safety; high rates of medical error.

In short, despite the insistent rhetoric of health, American economies simply do not prioritize it. That’s okay. There is no particular reason that the general health of a population should trump all other concerns. But given the evidence, how do we come to believe this disconnect between dismal health status in the United States and the entitlement to normative health and life span? What kind of management has this necessary disavowal required? And what about the obverse of this question: how do these stories constitute those who are forced to drop out? After all, if survival is a moral and financial

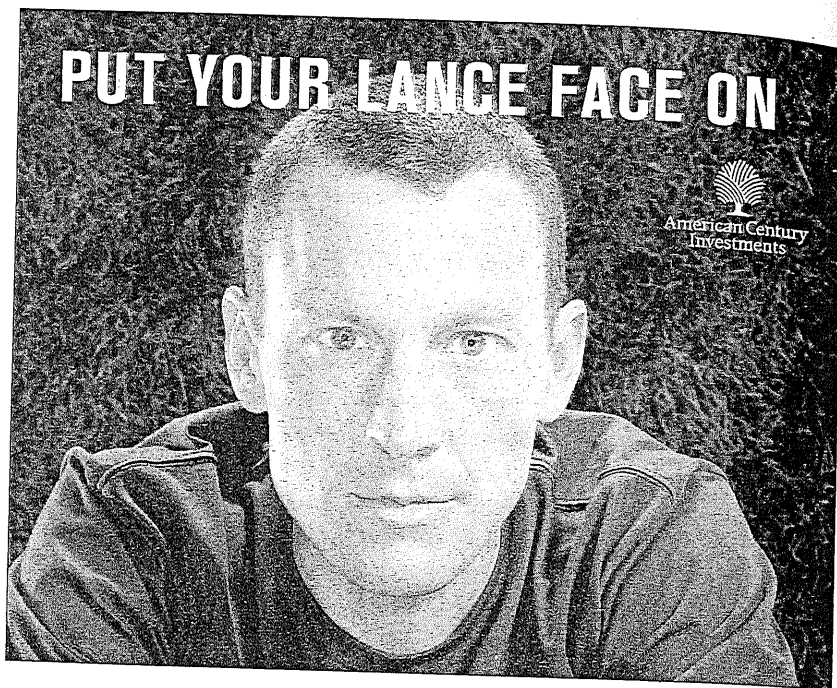


Figure 13.1: The 2006 “Put Your Lance Face On” campaign from American Century Investments. This version of the promotional photo omits the warning, required in print advertisement publications, that it is possible to lose money by investing (included in the original).

expectation and entitlement, then mortality must be constituted as something outside of normal life, even though these early deaths pay for pensions and other deferred payments. Even though everyone will die. I hypothesize that stigma and shame offer a way to examine and challenge ideals of health and the ways that normative life spans have been constructed.

Accumulation

For analytical wealth in this matter, nothing beats a recent advertisement for American Century Investments that featured Lance Armstrong (figure 13.1).

Armstrong has provided something of a translational figure for the nexus of industry, cancer, and humanitarianism that constitutes the discourses of cancer survivorship, foregrounding and even heroizing cancer survivors. His own story relentlessly underpins this cultural work.

While some accounts of Armstrong’s success go so far as to credit chemotherapy for literally rebuilding his body as a cycling machine, and others link his drive and success to his cancer experience, Armstrong continually presents himself in public as a survivor, claiming that his greatest success and pride is having survived cancer. In his autobiography, *It’s Not About the Bike*, Armstrong describes how, when diagnosed with testicular cancer in 1996, he actively sought the best care available to overcome a poor prognosis. He chose a doctor who offered a then-new treatment that turned out to revolutionize the treatment for testicular cancer, turning the disease from a high-risk cancer to a largely curable one even in its metastatic iteration. This coincidence in the timing of his disease and this new treatment has enabled him to make his own agency in finding medical care into another inspirational aspect of his cancer survival story.

In fact, cancer treatments are some of the most rote, protocol-driven treatments in medical practice, perfect examples of what historian Charles Rosenberg has detected as the rationalization of disease and diagnosis at the expense of the humanness of individual patients.⁵ Yet Armstrong’s story serves several purposes. It overemphasizes the role of agency in the success of cancer treatment, a view that correlates well with the advertising messages of high-profile cancer centers. It overestimates the curative potential of treatments for most cancers, something we would all like to believe in. And it propagates the myth that everyone has the potential to be a survivor—even as, ironically, survivorship against the odds requires the deaths of others.

This Armstrong story comes with real social costs for many people surviving with and dying of cancer. Miriam Engelberg’s graphic novel, like so many cancer narratives, ends abruptly with the recurrence of her metastatic disease and her subsequent death. One prominent page of her book has a cartoon with her holding a placard stating, “Lance had a different cancer,” in response to her friends’ and colleagues’ comparison of her with Armstrong and their terrifying denial of her actual situation.⁶ So, while many cancer survivors consider Armstrong an icon and inspiration, others feel that he is misrepresentative of the disease. He at once gives them impossible standards of survivorship while at the same time building his heroism on the high death rates of other cancers.

The American Century Investments advertisement summons the reader to “Put Your Lance Face On.” After gazing into the close-up image of a determined looking Armstrong and thinking quietly to oneself, “what the fuck?” one reads that “putting on a Lance face” “means taking responsibility for your future. . . . It means staying focused and determined in the face of challenges. When it comes to investing . . .” This ad is about Lance the Cyclist, sure; it

is also about Lance the Cancer Survivor. Control over one's future holds together the common thread of cancer survival, Tour de France victory, and smart investing. But all this folds into the tiny hedge at the bottom of the ad: "Past performance is no guarantee of future results . . . it is possible to lose money by investing." Even the Lance Face can see only so far into the future.

This warning, necessary by law, echoes a skill essential to living in capitalism. In her study of market traders, Caitlyn Zaloom finds that "a trader must learn to manage both his own engagements with risk and the physical sensations and social stakes that accompany the highs and lows of winning and losing. . . . Aggressive risk taking is established and sustained by routinization and bureaucracy; it is not an escape from it."⁷ The conflation of Armstrong as athlete and cancer survivor in this ad offers the perfect personification of market investing, since the healthy functioning of a capitalist order requires a valorization of focused determination and responsibility for one's future. By now a truism, liberal economic and political ideals require citizens to place themselves within a particular masochistic relationship to time. What else but an ethos of deferred gratification would allow such retirement plans to remain solvent?

As offensive as this ad is in its use of disease to create business, Armstrong's story constitutes a culturally acceptable version of courage, cancer, and survival that serves to comfort a population with increasing cancer rates, and the ad puts to use and propagates these notions of survivorship. As one person wrote about giving Armstrong's autobiography to her mother as she was dying of cancer, "I wanted her to be a courageous 'survivor' too. I think we find it less creepy or at least difficult when people assume the role of survivor, where they pretend they're going to live an easy and long life."⁸

You can be angry at cancer; you can battle cancer. One campaign underwritten by a company that builds radiation technology even allows people to write letters to cancer. But to be angry at the culture that produces the disease and disavows it as a horrible death is to be a poor sport, to not live up to the expectations of the good battle and the good death witnessed everywhere in cancer obituaries. A bad attitude of this genre certainly will never enable you to become an exceptional patient. It's as though a death threat blackmails cancer anger and frustration. But more astonishing still is the way in which this "poor sport" characterization carries over even into other cancer events.

There is nothing wrong with having fun while making money. As one under-forty person who has been living in the cancer complex for over two decades said, "A fundraiser is where you invite people to a big fun event, serve great drinks, and do everything possible for them *not* to think about

cancer."⁹ You do want people to feel good and strong so that they will open their wallets, but this humanitarian charity model ("Swim for women with cancer!") obscures the politics and paradoxes of such divisions. As one person organizing a fundraiser for her particular and rare cancer said as she thought about asking her doctors to attend her event, "They've made enough money off my cancer, they could pay some back."¹⁰ I signed on as the mixologist for the event and spent several hours designing circus-themed drinks with little cotton candy garnishes.

Time and Accumulation

Armstrong's class, gender, and curable cancer allow his iconic status to overshadow the simple fact that cancer can completely destroy your financial savings and your family's future. Sixty percent of personal bankruptcies in the United States result from the high cost of health care.¹¹ This news, wonderful for people working in the healthcare industry since many people will pay anything for medical goods and services, means that cancer can be a long, expensive disease, paid for over generations.

When one's financial planner asks, semi-ironically, how long you plan to live, he calls up the paradox of survivorship. Middle- and upper-class Americans are asked to plan for an assumed longevity, and to be sure, a properly planned life span combined with a little luck comes with its rewards. But in times of trouble, the language of financial service starts to show cracks, even for healthy youngish people. The other day, when interviewing a Fidelity representative about my decreasing retirement account, the representative kept using the phrase "as your retirement plan grows." When I pointed out that it had, in fact, shrunk by 45 percent, he just stared at me blankly. When, as an experiment, I asked him about people who don't make it to the age of sixty-five, he pleaded, "You really need to think about it as a retirement plan."

No matter how we are interpellated to think about these accounts, non-normative life spans tell us about the ways that capitalist notions of time and accumulation work both economically and culturally. Many kinds of economic benefits, for example, are based in an implied life span: you work now, and we'll pay you later. Social Security benefits are granted on the basis of how much you have put into the system over the years, and they last until you or your survivors are no longer eligible. Middle-class jobs often include not only salaries, but what are known as "deferred payments." Pensions fall into this category, as do penalty-free retirement savings, and the benefit some academics get of partial payment of their children's tuition.

If you croak, some of these contributions may revert back to your estate; others may be disbursed to qualifying survivors; others will be recycled into the plans that will pay for the education of your colleagues' children. As with any insurance policy, such calculations require that the state or the employer offer salary packages in the form of a financial hedge on your mortality and calculate the averages over the whole workforce. Payments for those who get old depend on the fact that some will die young. It's not personal; it's statistical.

Actually, I take that back. I guess there is not much that is more personal than your sex life, and if you are heterosexual and married—that is, if you say you are sleeping with one person only and that person is of the opposite sex and over a certain age—your cancer card will play more lucratively. If you fit these criteria, you may be able to pass on these benefits and enable your loved ones to pay off some of your medical debts or provide a way toward a more comfortable life in (and sometimes because of) your absence. The survivorship of a spouse is a state-endowed right, enabled in the form of a cash benefit and various forms of tax relief. A husband's or wife's death will enable his or her spouse to receive Social Security checks for decades. This cash enables a sort of proxy-survival by fulfilling your responsibility toward the support of your spouse and possibly the support of your children.

This is precisely how one person explained to me his reasoning behind a recent change of genders: he can now legally have a wife, legally bring her into the country, and legally offer her the protections of Social Security. For the same reasons, my lawyer advised me to marry a man, so that my husband could give the survivor-cash to my girlfriend. For the same reasons, my mother was bummed out when I turned out not to be straight. Health is social and institutional as well as physical. Capital and family legitimate and live through each other, in some sense rendering each other immortal.¹²

Social Security might be seen as ensuring that those who do not conform to its measures of social legitimacy—people with forms of support that do not fall into the marriage category—are not given the forms of security into which they are asked to pay while they live. Straight marriage presents a form of cultural longevity for the institution of marriage, and the labor of those who cannot partake in such survivorship literally underwrites the security of the individuals who can.¹³

Historians of marriage have documented how ideas about the well-being of children led to these forms of social support. But take a closer look, and you will see that it's only some children who benefit from these protective policies. Here's an example. My employer offers a housing benefit that gives

some employees financial assistance in purchasing a house. It also describes death as a "severed relationship." The relationship between my employer and an employee of the university can pass through a surviving partner—they included same-sex couples in their benefits plan in 1992, albeit as taxable benefits rather than the untaxed benefits that straight people receive—such that a surviving partner may continue to live in a house purchased with the help of this fringe benefit. However, if an employee has children and no partner, the relationship is severed and the children are "SOL" (shit out of luck); they must sell the house no matter what the market is like and return the down payment loan to the employer. The debt cycles of illness and the early deaths of a parent are thus differently borne out through what counts as legitimate survival, thus reinforcing and rewarding normative social structures.

But more important to my argument here, these retirement and Social Security benefits offer one means by which the terms of life span come to be taken for granted by the middle class in the United States. They make life span into a financial and moral calling, albeit one that the state will be willing to partially subsidize in the event of the deaths of the citizens who fulfill its principles of economic and sexual responsibility.

All this rests on a premise critical to economies in America: time and accumulation go together. You need the former to get the latter, and you have more stuff as you get older. No wonder people want to freeze themselves. Seriously. Cryonics offers an obvious strategy to maximize capitalist accumulation. On my salary, I'll be able to pay for my kids' college tuition in one hundred and fifty years. If I could freeze myself and my daughters and let my savings grow over that time, then come back to life after all the work of accumulation has been done for me, well, I could take full advantage of both the deferral and the gratification.¹⁴ This may sound ludicrous, but it's basically the next step of what is already happening; people already freeze their eggs and sperm in order to maintain their fertility to a point at which they have gained the sort of financial security that time and accumulation (are supposed to) bring.

While cryonics suspends biological life as capitalism proliferates, uncontrollably duplicating cells work to immobilize biological life. Cancer parodies excess. It could not be farther from the metaphors of an external enemy attacking the body imagined by visions of targeted chemotherapy, the broad political imaginary of the war on cancer, or the trope of the courageously battling and graciously accepting patient. If wealth rots the soul, accumulating tumors rot the host. It just grows, sometimes as a tumor you should have noticed but didn't, sometimes as a tumor you can't help but notice but can't

remove. It may just live there; you may touch it each day. It may disappear or it may wrap its way around your tongue. Either way, its changing size may make it seem living or dying. It inhabits a competing version of time, not yours, to which such things as savings and retirement are supposed to correlate, but its own, to which such words as “apoptosis” and “runaway” accrue. These versions of competing time reveal a lot about life spans in capitalism.

Conclusion

Alas, the Lance Face aims not toward the growing demographic of cancer survivors whose bodies experience the fissures of the immortal pretensions of economic time. Unlike many people who calculate their odds and cash out their retirement policies after diagnosis, or the friends of mine who told me that I was the inspiration for them to live in the moment and renovate their home, or those ads that regularly appear in *Cure* magazine that offer to buy the life insurance policies of people with cancer in exchange for a percentage, the Lance ad replays tiresome injunctions to future thinking, saving, and determination. The ad encourages the potential consumer of banking products to work in the broader interests of capital. Simply put, the ad uses cancer for its own ends and is able to do so because of the way that cancer rhetorics have so unquestioningly overlapped with notions of progress and accumulation in capitalism.

The cultural management of cancer terror follows to some extent the Cold War strategies of damping nuclear terror. You may have wondered why the phrase “you are the bomb” presents itself as something of a compliment whereas, in a romantic situation, the comment “you are the gas chamber” may not go over that well. Anthropologist Joseph Masco has analyzed how Americans didn’t just turn the threat of nuclear annihilation into atomic cafes, bikinis, and B-52 cocktails on their own; we were taught to survive through specific governmental programs sought to manage the emotional politics of the bomb. Nuclear terror, as a paralyzing emotion, was converted into nuclear fear, “an affective state that would allow citizens to function in a time of crisis.”⁵ Such emotional management required a two-pronged approach. First, citizens were asked to “take responsibility for their own survival.” Second, enemy status was displaced from nuclear war onto public panic, such that the main threat was perceived as inappropriate reactions to detonation, rather than to the bomb itself. Even with increased bomb testing and its release of radiation into the atmosphere, the discovery of high levels of radiation in American flesh and teeth, and the corresponding increasing of cancer rates along fallout routes and among nuclear workers, the nuclear

threat was always constituted as coming from the outside, never as the predictable and calculated risk of American nuclear programs. In that sense, the forms of emotional management that resulted from military technologies underpin cancer culture in the United States as much as the technologies of chemotherapy and radiation do.

To be sure, the increasing use of the language of survivorship in mainstream cancer culture offers a welcome change from the days when people with cancer were asked to use plastic cutlery so as not to infect those around them or were not told of their diagnoses in order to protect them. Now, the person who survives cancer walks a fine line between courage and deception, horror and the quotidian, in ensuring that American models of health retain their normative status. Lance Armstrong offers the perfect venue for such disavowals, as he currently rises as if in a second coming, high above the Nike building at Union Square in San Francisco and other American cities, his Lance face in perfect shape, with another sufficiently vague, sportsmanly tag line: “Hope Rides Again.”

What if, instead of some broad and grammatically, if not affectively, meaningless aim as marching and riding “for hope,” fundraisers attempted to ban any one of the thousands of known carcinogens in legal use? What if we walked, ran, swam, rode not for hope, but against PAH, MTBE, BPA or any other common carcinogen? Such an effort would require naming the problem rather than the symptom, and recognizing how we are all implicated. It would require that we invest in cancer culture not as a node of sentimentality but as a basic fact of American life.

NOTES

1. Bernie S. Siegel, *Love, Medicine, and Miracles: Lessons Learned about Self-Healing from a Surgeon's Experience with Exceptional Patients* (New York: Harper and Row, 1986).
2. *Oxford English Dictionary*, 2nd ed., s.v. “Shame.”
3. Again, I think it is easier to speak facetiously from the position of having a non-metastatic diagnosis.
4. Stephen Ohlemacher, “US Slipping in Life Expectancy Rankings,” *Washington Post*, August 12, 2007, <http://www.washingtonpost.com/wp-dyn/content/article/2007/08/12/AR2007081200113.html>.
5. See Charles E. Rosenberg, “The Tyranny of Diagnosis: Specific Entities and Individual Experience,” *The Milbank Quarterly* 80, no. 2 (June 2002): 237–60.
6. Miriam Engelberg, *Cancer Made Me a Shallower Person* (New York: Harper, 2006).
7. Caitlin Zaloom, “The Productive Life of Risk,” *Cultural Anthropology* 19, no. 3 (August 2004): 365.

8. Personal correspondence with author, April 10, 2008.
9. Personal correspondence with author, March 15, 2009.
10. Personal correspondence with author, April 11, 2009.
11. See David U. Himmelstein, Deborah Thorne, Elizabeth Warren, and Steffie Woolhandler, "Medical Bankruptcy in the United States, 2007: Results of a National Study," *The American Journal of Medicine* 122, no. 8 (August 2009): 741–46.
12. These structures carry invisible costs even for straight people who believe themselves to be outside of these cycles. Think for example of the shooting of Harvey Milk and George Moscone. The short sentence given to Dan White for the shooting is usually ascribed to the fact that, since Milk was queer, the judge believed that his life was not worth much. Moscone was considered collateral damage. See *The Times of Harvey Milk*, dir. Rob Epstein, 90 min., Black Sand Productions, 1984.
13. This kind of structural attention to cultural institutions and actual care are understudied. For example, when President Barack Obama made an exception to his usual homophobic platform to call for allowing same-sex couples to be able to visit their partners in hospitals, he was making a way for partners to be able to love each other and to be able to share a deep experience. Advocacy and protection are huge parts of contemporary medical care. I have come across hundreds of examples of this in my years of research. This aspect of contemporary medical care includes everything from making sure that medical records are transferred properly or read, that medical allergies are made known, that machinery is working, that people wash their hands and are given the proper doses of medication. Such bedside advocacy is an enormous, and understudied, part of healthcare provision.
14. Tiffany Romain is working on an important dissertation on this subject in the Department of Anthropology at Stanford University.
15. Joseph Masco, "Survival Is Your Business: Engineering Ruins and Affect in Nuclear America," *Cultural Anthropology* 23, no. 2 (May 2008): 366.

In the Name of Pain

TOBIN SIEBERS

To be against health is to be for pain because human beings suffer from sickness. But to suffer from sickness is something of a metaphor. We supposedly *suffer* from diseases and disabilities whether or not they are painful. The man standing on the corner pointing the white cane suffers from blindness, but he has no pain in his eyes or anywhere else. The young woman walking to the local deaf club suffers from deafness, but her body does not hurt and she seems perfectly happy. The Iraq war veteran suffers from quadriplegia, although he cannot feel a thing in most of his body.

A disabled body is supposedly a body in pain, and pain represents for most people a source of terror and an affront to human dignity. Nothing seems more horrifying to human beings than to imagine a lifetime of future suffering. Pain is, however, notoriously subjective. The usual observation notes that it is difficult to share pain, that one person cannot really understand the pain of another.¹ But a second difficulty exists—quite the opposite—and it is rarely discussed: how frequently people impute feelings of pain and suffering to other people. It is astonishing how often one person assumes that another person is in pain based solely on appearance or circumstances. Passersby approach the man standing on the corner with the white cane and gush with great admiration over his bravery in the face of suffering and adversity. They blurt out to the young deaf woman that they themselves could not bear such hardship. Complete strangers feel compelled to tell the paralyzed veteran that they would rather be dead than be him. Such reactions may set off feelings of grief in the objects of pity if they are genuinely in pain, but they may just as likely respond with bewilderment to the fact that their happy existence represents a lifetime of suffering to absolute strangers who know nothing about their families, occupations, physical conditions, or daily circumstances. Such is the nature of pain in the human universe. In an instant and with little reflection, pain triggers powerful emotions, opinions, and judgments.

To speak in the name of pain is to resist these bad habits of thought. Pain is a motive force rarely questioned and stunning in its ability to engage us