Chronic profitability

ANDREW SCULL

S. Lochlann Jain

MALIGNANT
How cancer becomes us
290pp. University of California Press. £41.95
(US $60).
978 0 520 27656 6

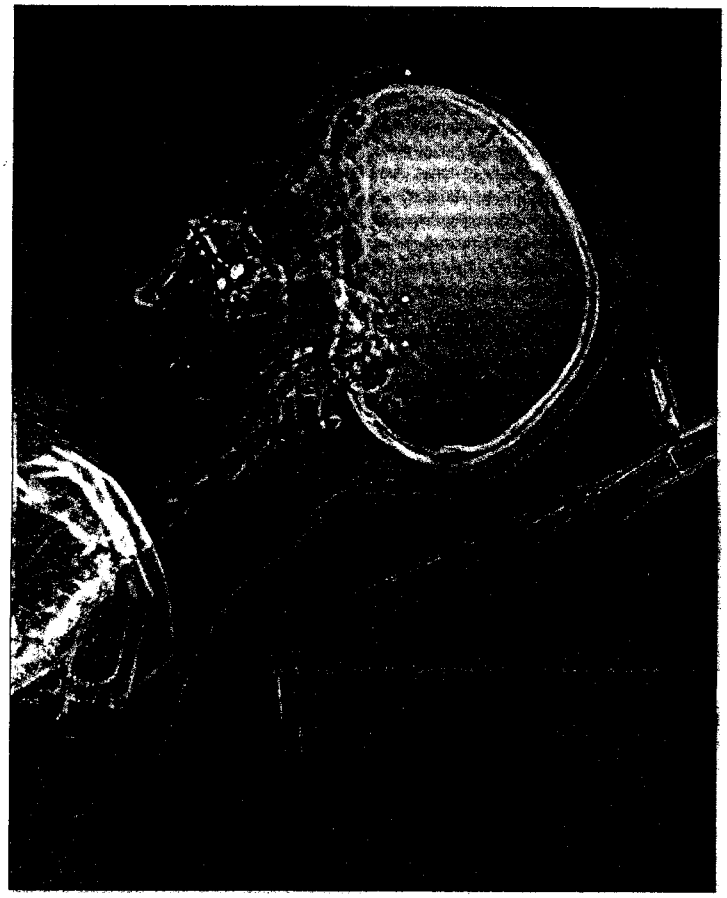
We routinely dissemble with ourselves. We do so on all sorts of occasions. Perhaps it is a condition of preserving a decent sense of who we are, of ignoring the ignoble, the less salubrious aspects of our selves. But we dissemble with ourselves most notably about our mortality. Intellectually, of course, we know we must die. It is our fate, like the rest of the animal kingdom, to die and to disappear: dust to dust, and ashes to ashes, as the Good Book would have it. But it is not a thought we dwell on. To the contrary, most of us rigorously (and for the most part successfully) suppress it, and plan and live our lives as though we shall go on forever. In old age, perhaps, the Grim Reaper becomes harder to ignore, and perhaps his attentions may even prove merciful as one wears down and wears out. But in youth and even middle age, mortality is for others. We have our whole lives left to lead. Except sometimes, abruptly, it turns out that we don't.

For two or three years, the patient has brought an odd set of symptoms to the attention of a physician. Perhaps two or three specialists have been consulted on the case. Each time, the patient's concerns have been minimized and brushed aside, dismissed with a wave of the hand that suggests that only a hypochondriac or an idiot would even raise them. And then, one awful day, a very different message is proffered: the symptoms are a sign of some invasive form of cancer. To the dread that now will cast an indelible shadow over one's future existence, however long or short that may turn out to be, is added a sense of anger and betrayal. Not only have the dice turned up snakes' eyes, but the doctors to whom one entrusted one's life have made a bad situation infinitely worse, for in misdiagnosing they have heightened the chances that the cancer growing within will prove to be beyond help. For that fateful mistake the physicians will likely suffer no sanction, save perhaps some brief qualm of conscience, easily brushed aside, while for the patient, the error will cost untold additional misery, perhaps even life itself.

Doctors, it turns out, dissemble too, misdiagnosing cancer in the young and early middle-aged, in part because cancer is disproportionately a disease of old age. Disproportionately, but not exclusively. Not coincidentally, nearly three-quarters of adults under the age of thirty-nine who are diagnosed with a malignancy have late stage (and therefore more deadly) cancers. And so these patients enter a malignant world, one defined by the malignancy and by what it portends, most especially the kinds of treatments that now beckon and come to define one's existence: mutilating surgery, poisonous chemotherapy, and radiation treatments whose side effects wrack the body with nausea, make one's hair fall out, and cause other, still more devastating systemic damage. These interventions seem as brutal in their way as the illness itself.

Lochlann Jain is a professor of anthropology at Stanford University. A trained ethnographer specializing in medical matters, she might have chosen to explore the world of cancer diagnosis, treatment, survival and death, but instead, it chose her. She was the patient in her early thirties whose symptoms were neglected and dismissed, and who suddenly found herself engulfed by a nightmare. Research in some sense was her antidote, her special recipe for coping with the anger that accompanied her misdiagnosis, and the fear and physical damage that she had to endure in the years that followed. But she has also been driven to look at the world of cancer in the United States, for though the disease may be universal, the peculiarities of the American political economy and culture indelibly mark the experience of those with malignancies. People everywhere suffer and die, or manage to survive, the onset of cancer. But to become a cancer patient in the United States in the twenty-first century, even if one is a privileged, white patient with excellent medical insurance and the unusual degree of job security that still accrues to the tenured academic, is to be drawn into a world that has some quintessentially American features.

"Cancer", as Jain discovers, "has the highest per capita price of the nation's medical conditions." Cancer patients "are cash cows", squeezed until they have no more resources left. In the end, many are driven to bankruptcy. Almost half of them will end up being harassed by calls from collection agencies, as if the agony of their illness and treatment and the prospect of premature death were not enough to wrestle with. Treatments improve at a glacial pace, if at all. The chemical cocktail used to treat breast cancer patients like Jain has remained essentially unchanged since the 1970s, and there are only fractional differences in survival rates. Yet somehow, the medical industry has turned a war defined largely by defeats into a financial bonanza. As with psychotropic drugs for the treatment of mental illness, it is precisely the relative therapeutic impotence of cancer chemotherapy that has made the treatment so valuable. Drugs that cure are great from the point of view of the patient, but not so great for the pharmaceutical houses. Chronic conditions are chronically profitable. Think of AIDS, asthma, arthritis, hypertension, diabetes, the build-up of lipids in the bloodstream and the blocking of arteries by cholesterol – or, more bathetically, the omnipresent Viagra and its clones, ministering to the contemporary epidemic of "sexual dysfunction".



A CT scan of a patient being treated with radiotherapy for brain cancer

There is another aspect of the American medical scene that is renowned and reviled: the prevalence of litigation. The misdiagnosis that leads many of the cancers of the relatively young to be discovered relatively late has inspired many a lawsuit. The legal theory that underlies the resort to the courts is the notion of "the lost chance", the diminished possibility of survival. Such suits are hard to win for all sorts of reasons, and restrictions on medical malpractice claims are making them less desirable cases for personal injury attorneys than they once were. Jain suggests that part of the motivation for Americans to sue anyway, wherever they can, is the absence of a social safety net and the desperate search for some way to offset the crushing costs of treatment. In her own case, she admits to other motivations: the simple desire to secure an apology from the doctor who had made such a life-altering mistake; and a desire to know more about how such a catastrophic error could have been committed.

Jain read omnivorously about therapeutics, about mortality statistics and stageing, about the epidemiology of various cancers. She wondered whether her own cancer had been triggered by the large doses of hormones she had voluntarily ingested when she agreed to be an egg donor for a friend, and ransacked the scientific literature for an answer. She delved into the experience of fellow sufferers and, initially with strong misgivings, she went to a retreat populated by fellow sufferers, many frequently too sick even to walk. It was a chance to acknowledge before a knowing audience feelings of loss, fears about pain, the loss of independence, despair at the prospect of death, the experience of how others in their intimate circle had responded to the news of their diagnosis – well or badly, clumsily or empathically – and to reflect on how little even one's intimates know about cancer. To her surprise, and despite the grief and heartbreak that were everywhere, the experience proved cathartic, a chance "to discover community, to rediscover the selves that had been stolen by the cancer complex".

Malignant is a sometimes curious confection of information about cancer and its therapeutics, and a narrative about Jain's own experience of being ill. To begin with, she is coy about her own malignancy – perhaps she is going to dissemble about what exactly her cancer diagnosis is – but the reticence does not last. She describes in unsparing detail her two mastectomies and how she coped with them; the experience of chemotherapy; what it means to be mutilated; the emotional pain she endured; how it feels to live with a particular prognosis (and not a good one); how she navigated her care (asked repeatedly, for example, to describe her pain levels on a scale from one to ten, "I became adept at knowing what number to say to get the amount of medication I wanted"). To date, obviously, she has survived the terrible odds that have confronted her. She has managed to rebuild her career and, more importantly, the life, that she, her partner and their children had built before the onset of her illness. Her book is an unusually personal look at the phenomenon of becoming a cancer patient and at what it is like to undergo cancer treatment. It is a remarkable achievement on many levels.